“KNOWLEDGE AND BURDEN AMONG CAREGIVERS REGARDING CARE OF THE PATIENTS WITH SCHIZOPHRENIA AT PSYCHIATRIC OPD, AIIMS, JODHPUR WITH A VIEW TO DEVELOP AN INFORMATION BOOKLET”

A Thesis submitted to the
All India Institute of Medical Sciences, Jodhpur
In partial fulfilment of the requirement for the degree

Master of Science in Nursing
(Psychiatric Nursing)
By
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2021

DECLARATION BY THE CANDIDATE

I hereby declare that the thesis entitled "Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet" is a bonafide work carried out by me under the guidance of Mr. Aashish Parihar, Assistant Professor, College of Nursing, AIIMS, Jodhpur. No part of this thesis has formed the basis for the award of any degree previously.

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CERTIFICATE BY THE GUIDE

This is to certify that the thesis entitled "Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet", is a bonafide work done by Suman Bhatia in partial fulfilment of requirement for the award of M.Sc. (Nursing) degree of the All India Institute of Medical Sciences, Jodhpur under the guidance of undersigned. She has carried out the work at College of Nursing, All India Institute of medical Sciences, Jodhpur.

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This is to certify that the thesis entitled “Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet”, is a bonafide research work done by Suman Bhatia under the guidance of Mr. Aashish Parihar, Assistant Professor, College of Nursing, AIIMS, Jodhpur.

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Signature

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LIST OF ABBREVIATIONS USED

Abbreviation	**Elaborated form**
AIIMS:	All India Institute of Medical Sciences
χ2:	Chi square
df:	Degree of freedom
f:	Frequency
N:	Number
OPD:	Out Patient Department
%:	Percentage
SD:	Standard Deviation
WHO:	World Health Organization
ZBI:	Zarit burden interview

ABSTRACT:

INTRODUCTION: According to WHO mental disorders are the leading causes of ill-health and disability worldwide. Around 450 million people currently suffer from such conditions. Under psychotic illness schizophrenia is most common. It involves disturbances of thinking, perception, affect and social behaviour. According to WHO Schizophrenia is a chronic and severe mental disorder affecting 20 million people worldwide. Globally, Schizophrenia contributes 13.4 million years of life lived by patient with disability to burden of disease. This burden includes influence on physical, psychological and emotional health of family members.

OBJECTIVES: To assess knowledge and burden among caregivers of the patients with schizophrenia and to find out association between level of knowledge and level of burden with selected socio-demographic and patient related variables of caregivers

METHOD: A nonexperimental descriptive research design with quantitative approach was conducted on a sample of 200 caregivers of the patients with schizophrenia. Data were collected through face to face or telephonic interview by using non-probability consecutive sampling technique. Self-structured knowledge questionnaire was used to asses level of knowledge and Zarit burden interview was used to find out level burden among caregivers of the patients with schizophrenia.

RESULT: The study reveals that among 200 caregivers 21% participants were having good knowledge, 39.5% were having average knowledge and 39.5% were having poor knowledge. The mean score of the knowledge was 16.34 with the standard deviation of ±4.72. Regarding burden 12% of the caregivers were having little or no burden, 32% of the caregivers were having mild to moderate burden, 43.5% of the caregivers were having moderate to severe burden and 12.5% of the caregivers were having severe burden. The mean score of the burden was 42.03 with the standard deviation of ±15.14. Regarding knowledge gender, education, employment status, family income and impact of caregiving on employment were statistically significant with the level of knowledge at $p<0.05$. Regarding burden age, education, family income and impact of caregiving on employment were statistically significant with the level of burden at $p<0.05$. On the basis of mean % distribution researcher identified lack of knowledge in following domains of knowledge questionnaire such as General awareness about schizophrenia, Identification of symptoms, Measures for Safety and hygiene, Treatment compliance and Management of symptoms including social skill training. Therefore, the basis of information booklet development were these domains.

CONCLUSION:

The current study will help health care professionals to understand the impact of schizophrenia on the caregivers. Family support is an important aspect of the psychiatric treatment modality, by conducting such studies will definitely help to understand the patient and caregiver’s problems and difficulties faced during the treatment course and while providing care to the patients.

KEYWORDS: “Knowledge’’, “Burden’’, “Caregivers of the patient with schizophrenia’’, “Information booklet’’

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CHAPTER-I

INTRODUCTION

CHAPTER-I

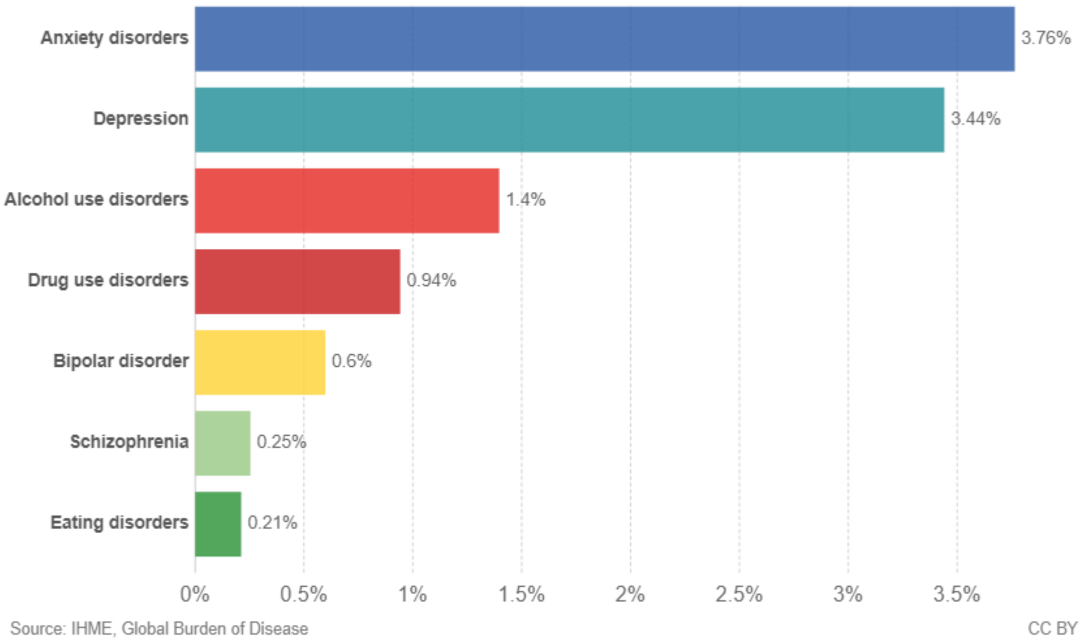
INTRODUCTION

‘‘Mental health is not a destination, but a process. It’s about how you drive, not where you’re going.’’ (Noam Shpancer)

Background of the study:

Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.[1] (WHO)

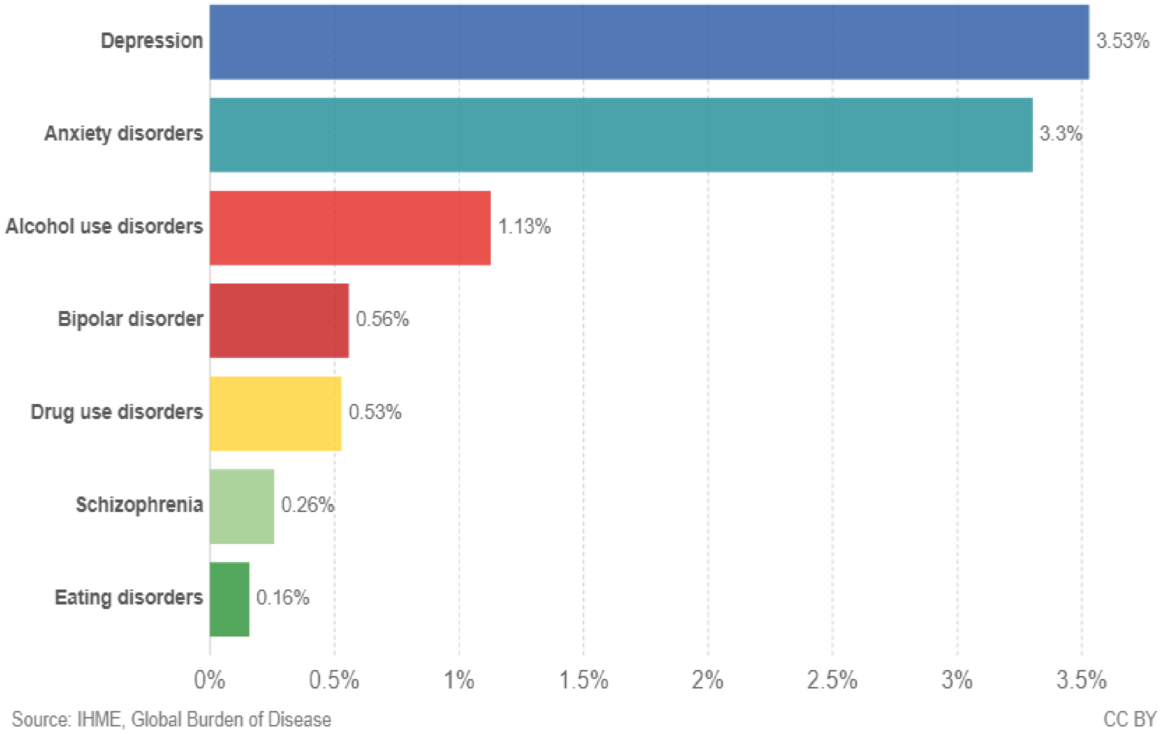
According to WHO mental disorders are the leading causes of ill-health and disability worldwide. Around 450 million people currently suffer from such conditions.[2] A recent index of 301 diseases found that mental health problems are one of the main causes of the disease burden worldwide.[3] Worldwide, the highest number of people had an anxiety disorder, that is at around 4 percent of the population. Following data represent the global prevalence of mental health disorders.[4]



Source: IHME, Global Burden of Disease

Fig. I Prevalence of mental and substance use disorder, World, 2017.[4]

In India, the highest number of people had depression, that is at around 4 percent of the population followed by anxiety disorder. Following data represent the Indian prevalence of mental health disorders.[4]



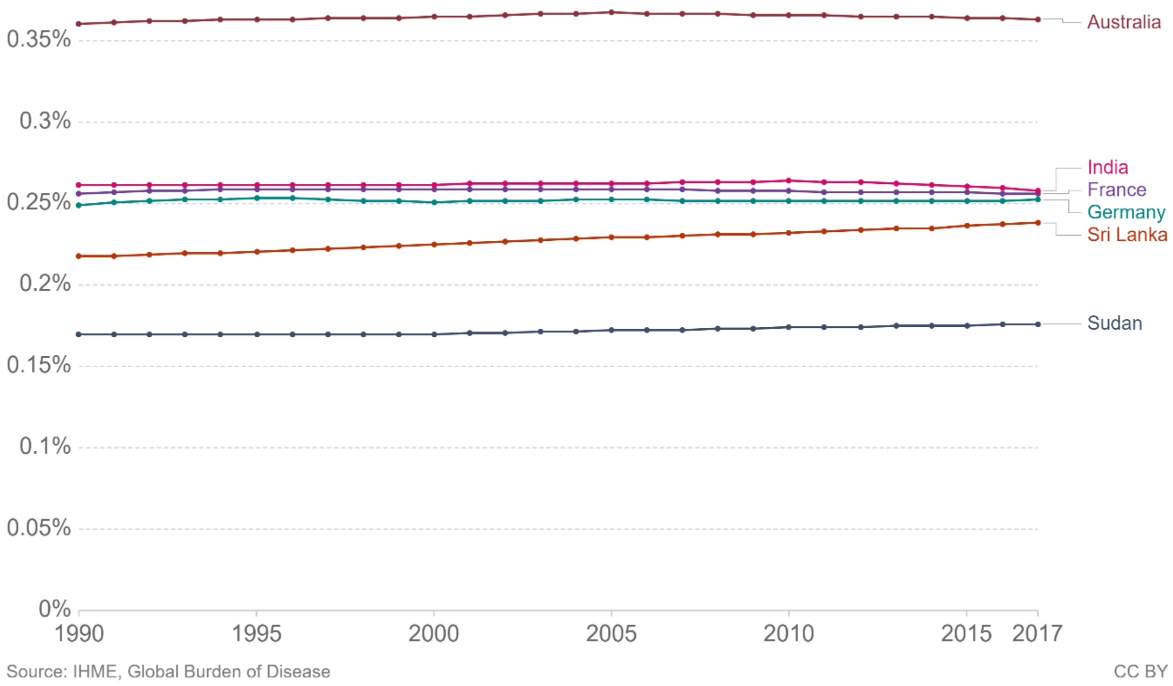
Source: IHME, Global Burden of Disease

Fig. II Prevalence of mental and substance use disorder, India, 2017.[4]

According to Global Burden of Disease Study 1990–2017, the burden of mental disorders across the states of India shows that among the major mental disorders that manifest predominantly during adulthood, the crude prevalence for both depressive disorders and anxiety disorders was 3·3%, whereas bipolar disorders had prevalence of 0·6% and schizophrenia 0·3%.[5]

According to Global Epidemiology and Burden of Schizophrenia, Globally, prevalent cases increased from 13.1 million in 1990 to 20.9 million cases in 2016. Globally, Schizophrenia contributes 13.4 million years of life lived by patient with disability to burden of disease.[6]

The prevalence of schizophrenia ranges from 0.2 to 0.4 percent across countries. Approximately, 20 million people in world had schizophrenia in 2017; Regarding gender the number of men and women affecting with schizophrenia was around 10 million each. Comprehensively, the prevalence of schizophrenia is slightly higher in men than women. The following data represent global-level data on the prevalence of schizophrenia[4]



Source: IHME, Global Burden of Disease

Fig. III Global level data on prevalence of schizophrenia[4]

The term schizophrenia was given by the Swiss psychiatrist Bleuler. Schizophrenia involves disturbances of thinking, perception, affect and social behaviour. According to diagnostic and statistical manual of Mental Disorders there are five subtypes of schizophrenia: paranoid schizophrenia, hebephrenic schizophrenia, catatonic schizophrenia, Undifferentiated schizophrenia and Residual schizophrenia. Although the clinical presentation of schizophrenia varies, but following symptoms can always be observed like disorder of thought (such as loosening of associations, poverty of speech and use of idiosyncratic expressions etc.), Delusions (Ideas of reference, control or persecution), Hallucinations (especially auditory hallucinations and abnormal physical sensations are the most common), Abnormal affect (such as reduction in emotional intensity or inappropriate affective responses) and Disturbances in motor behaviour (such as adopting abnormal positions for longer duration; repeated or aimless movement etc.).[7]

Schizophrenia typically begins in late adolescence or early adulthood. The treatment of schizophrenia is seen effective with antipsychotic medicines and psychosocial support. Over 80% of people with schizophrenia can be free of relapses at the end of one year of treatment with antipsychotic drugs along with family intervention. The person with schizophrenia can live a productive life and be integrated in society with appropriate treatment and social support.[8]

In India, families represent the most important means for providing care of people with mental illness. Families provides all aspects of care to their patients such as supervision of the regular intake of medication and also fulfill physical, emotional and basic needs of patients. Families also experience negative attitudes and discrimination in various social situations while providing care to the patients. In addition, families encounter many challenges and burden. This burden includes impact of schizophrenia on family members like it affects physical, psychological and emotional health of family members. Family members may become irritated, frustrated, feel unable to cope and often feel trapped, discouraged or exhausted by the stress of their daily struggle for providing care to patients. Therefore, involving the family members in treatment and reducing their burden is essential.[9]

Another important aspect about schizophrenia is its economic impact on family which includes the costs which is directly related to treatment (like paying consultation fees, purchasing medicines for patients, admitting patients in hospital etc.) and the costs which is indirectly related to treatment (like loss of employment of patients with schizophrenia and caregivers potential for doing job etc). Also, some patients of schizophrenia need to be cared by family members on daily basis. Because of that family member who is providing care cannot perform his/her job appropriately and potential income of family is lost. In addition, the patients may lose their job or unable to get job because of their illness. Both scenarios represent a major loss of potential income of family and family may undergone through a major financial burden. This financial burden leads to feelings of shame and guilt in patients with schizophrenia and become source of intra-familiar tension and uncomfortable reactions towards the ill family member.[9]

Therefore, for promoting mental health WHO has given Mental Health Action Plan (2013-2020), that recognizes the essential role of mental health in achieving health for all people. The plan includes four major objectives:

- To provide more effective leadership and governance for mental health
- To provide comprehensive, integrated mental health and social care services in community settings
- To implement strategies for promotion of mental health and prevention of mental illness
- To strengthen information systems, research and evidences.[8]

WHO has also given Mental Health Gap Action Programme (mhGAP), launched in 2008.This programme focuses on capacity building of non-specialized health-care workers with a view to promote mental health at all levels of care.[8]

NIMHANS (National Institute of Mental Health and Neuro Science) has also taken initiative for the schizophrenia patients and started Schizophrenia Clinic. In this clinic, comprehensive clinical care has been delivered by multidisciplinary team to patients with schizophrenia through Individualized Schizophrenia Treatment and Re-integration (InSTAR) Program. Following interventions has been done under this programme like comprehensive clinical assessment, psychopharmacological treatments, psychosocial interventions including group therapy, cognitive therapy and yoga-based interventions. In addition, ORACLES – Objective Risk Assessment Care & Liaison for Early Schizophrenia, is also available in the schizophrenia clinic for the patients with early course of schizophrenia. ORACLES, gives emphasis on early intervention approaches, understanding the response of medications, identifying family members who needs close monitoring and care, identification of prodromal symptoms, measures to prevent psychosis and initiating early rehabilitation strategies.[10] These are helpful for the patient as well as their caregivers to provide comprehensive care.

Similarly, SCARF (Schizophrenia research foundation) initiate, conduct and support research programs on the biological, social and psychological aspects of schizophrenia and mental illness to further knowledge of treatments and methods of caregiving. It also provide integrated, comprehensive, cost effective and accessible mental healthcare to the mentally disabled people, give emphasis on psychosocial rehabilitation especially employment support, initiate and implement mental health policy changes that will enable mentally ill people to participate fully in social processes and increase social awareness about mental illness, disability, treatment and other welfare measures.[11]

Therefore, for maintenance of mental health collaborative effort of family, community and social services is necessary to enhance the knowledge and reducing burden related to mental illness.

Need for the study:

‘‘Where there is neglect, there is little or no understanding. Where there is no understanding, there is neglect’’[2]

According to WHO Schizophrenia is a chronic and severe mental disorder which is affecting 20 million people worldwide. It is also associated with considerable disability and affects educational and occupational performance. In addition, stigma related to disease, discrimination and violation of human rights of people with schizophrenia is common.[12]

According to an e-newspaper, Patrika there were two cases came to AIIMS, Jodhpur which shows that caregivers are having lack of knowledge regarding care and treatment of the patients with schizophrenia. In one case a 24 years old, male patient having schizophrenia brought to AIIMS, who had burn marks on his both hands, as family members took the patient to Faith-healers after getting mental illness, where the patient was treated with burning by hot iron rod on both hands. After that disease got worsened and patient was brought to AIIMS for further management.[13]

In another case a 40 years old, female patient with schizophrenia was restrained by family member through shackles. After many years they brought her for treatment.[13]

These incidences show that caregivers are having lack of awareness regarding disease condition and available treatment option.

According to a study carried out by Suryani S, et al (2019) found that among 100 respondents 31% were having good knowledge, 42% respondents were having sufficient knowledge, and 27% were having insufficient knowledge. Regarding perception, 66% respondents had a positive perception and 33% had a negative perception. Regarding burden, 42% respondents were having moderate to heavy burden levels, 23% were having a very heavy level to heavy burden, and 3% were having very heavy levels of burden. The study concluded that frequency of health education and sharing program for families is essential to increase the knowledge and reduce the burden of families. [14]

Another study accompanied by Shinde M, et al (2014) shows that among 50 caregivers of the patients with schizophrenia, 30% had no prior knowledge about the schizophrenia and got the information first hand by patient's experience; whereas, 10% got the information from friends, 30% got from health workers and remaining 3% got the information from the local newspaper. Regarding symptoms of schizophrenia caregivers were asked to describe the different symptoms of their patients 74% responds replies Insomnia, 46% replies antisocial behavior, 42% replies physical aggression, 28% replies verbal aggressiveness, and 26% respondents replies isolation and withdrawal. The supportive interventions that caregivers recommended for the patients were family support (78%) and counselling (72%) were highly recommended, followed by others such as, rehabilitation, finance, stopping smoking and awareness. It was concluded that educational programmes for the relatives of patients are needed to enhance their knowledge.[15]

Another study carried out by Mishra SK, et al (2016) reveals that among 36 caregivers of admitted patient of schizophrenia, 47.2% caregivers reported suffering from severe burden. And it was found that the most severely affected areas were physical and mental health, taking responsibility of patients, caregiver's routine and patient's behavior. The study concluded that caregivers of the patients with schizophrenia suffered from significant burden and require additional care to help them alleviate their problems.[16]

Another study conducted by Kumari S, et al (2009) reports that among 50 spouses of patients with schizophrenia 60% of spouses of female schizophrenia patients experienced moderate burden and 40% experienced severe burden. Similarly, 52% of spouses of male schizophrenia patients experiencing moderate burden 36% experiencing severe burden. Surprisingly, in 12% of the spouses of male schizophrenia patients, no burden was found.[17]

All these data reveal that caregivers of the patients with schizophrenia are having lack of knowledge regarding disease condition, care of the patients and adopting treatment for the disease. Along with this, caregivers are also having burden related to care of the patients. Therefore, researcher felt the need to find out level of knowledge and burden among caregivers of the patients with schizophrenia and wants to enhance knowledge and reduce the burden of caring by developing an information booklet for them.

Aim:

- To assess knowledge and burden among caregivers of the patients with schizophrenia.
- To develop an information booklet for caregivers of the patients with schizophrenia.

Statement of Problem:

Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet.

Objectives:

1. To assess the level of knowledge among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur
2. To assess the level of burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur
3. To determine association between level of knowledge and selected socio-demographic and patient related variables of caregivers
4. To determine association between level of burden and selected socio-demographic and patient related variables of caregivers
5. To develop an information booklet having essential information regarding care of the patients with schizophrenia

Operational definitions:

- **Knowledge:** It refers to awareness of the caregivers regarding care of the patients with schizophrenia that will be measured by using self-structured questionnaire.
- **Burden:** In this study, burden refers to a negative experience faced by caregivers that is stigma, worry, shame and guilt that will be measured by using Zarit burden interview.

- **Caregiver:** Caregiver is an individual such as family member or guardian who is staying with patient from at least one year and taking care of the patient most of the time.
- **Psychiatric OPD:** A setting of the AIIMS hospital for the diagnosis and treatment of patients affected with acute or chronic mental illness.
- **Patient with Schizophrenia:** Patient who is diagnosed with schizophrenia.
- **Information Booklet:** A small, thin book with paper covers, giving information about schizophrenia and care of the patients with schizophrenia.

Delimitations:

The study is confined to:

a) Caregivers of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur.

b) As self-structured interview schedule is used so, caregivers who are having speech and hearing problems are excluded.

c) The study is limited to the caregivers who are available at the time of the study

Summary:

This chapter deals with introduction, need for study, aim of study, problem statement, objectives, operational definitions and delimitations of the study.

CHAPTER II

REVIEW OF LITERATURE

CHAPTER II

REVIEW OF LITERATURE

The second chapter deals with literature review. Literature review is knowing what is already known or work done on particular topic or area by scholars.

"A review of related literature is an essential aspect of scientific research. It is a written summary of the state of evidence on a research problem. It broadens the understanding of the research and help to gain an insight necessary for the development of a broad conceptual context into which the problem fits.[18]

(Polit and Beck)

A review of literature is a description and analysis of the literature relevant to a particular research or topic. It provides an overview of the work that had been already carried out, the key researchers who did that work, the questions already answered regarding a particular area of research interest, methods and methodologies used to answer the particular questions and the prevailing theories and hypothesis.

The review of literature also provides a solid background for a research study. The objectives of the review are to discover certain aspects that need to be included into the study to confirm or refuse earlier findings, to find certain data that may be available in interpreting the conclusion of the study. It was also necessary to ascertain, what has already been done in the field of study and what more needs to be done.

Bhat BA, Dar SA, Mir RA, Hussain A (2020) carried out a cross-sectional study to find out caregiver burden and quality of life. A total of 75 patients with schizophrenia and their caregivers were selected as sample. It was found that QoL was significantly correlated with burden on caregivers and duration of illness of patients. Among 75 caregivers 64% perceived mild-to-moderate burden. The caregiver burden was correlated with negative symptoms of patients. The burden perceived by caregivers was significantly predicted by their negative symptom scores. Researcher concluded that negative symptoms in patients were the only predictor of caregiver burden. [19]

Yu Y, et al (2020) carried out a study on 264 community-dwelling primary family caregivers of schizophrenia patients. The data were collected by using face-to-face interview. It was found that, in both types of caregivers, parent caregivers report significantly higher subjective burden than spouse caregivers. Beside this, both types of caregivers report comparable rewarding feelings about caregiving. Researcher concluded that family intervention programme should be conducted to incorporate cultural values and beliefs in understanding caregiving, to support family caregivers.[20]

Challuri P, Bandela SG (2019) accompanied a cross-sectional study to assess caregiver burden in spouses of patients with schizophrenia at institute of mental health, Hyderabad. A total of 100 spouses of patients with schizophrenia were taken by using consecutive sampling technique. Result shows that 76% of the caregivers were having moderate burden. Severe burden was found in undifferentiated schizophrenia patients who were having >10year duration of illness and with severe disability. It was statistically significant at ($p<0.001$). Also, more burden was seen in female gender, self-employed spouses and in spouses who were financially dependent on patient. Researcher concluded that psycho- therapeutic interventions like psycho education, family and couple therapy may help the spouses to cope with illness and also to reduce the burden.[21]

Kwok FW, Michael W (2019) carried out a cross-sectional survey to find out the degree of stress and burden among caregivers of relatives with schizophrenia and early psychosis. A total of 454 caregivers were recruited. Data were collected by using face-to-face or telephone interview. Result reveals that 56.4% caregivers attributed most of their conflicts with ill relatives because of their own lack of knowledge of patient symptoms, 46.9% were due to other family members' lack of knowledge of patient symptoms or 43% due to the ill relative's refusal to take medications (43.0%). Nearly 30.2% caregivers had corresponding stress scores of 5. Regarding psychosocial problems, 78% caregivers experienced anxiety, 49.8% experienced reduced socialising and 45.8% experienced insomnia, respectively. Researcher concluded that community support services should be strengthened to cope with distress. [22]

Gunjahalli B, Chougule P M (2019) disseminated a study to find out perception of burden by caregivers of patients with schizophrenia in relation to symptom profile. A total of 85 patients and their caregivers were interviewed and information regarding sociodemographic details of the caregivers, patient's illness, present psychopathology, and burden of the relatives were collected. Result shows that positive symptoms caused greater burden in caregivers as compared to negative symptoms. Burden increased with increasing severity of negative symptoms. There was no significant influence of duration of illness and compliance to treatment was seen on caregiver's perception of burden. The study concluded adequate that there is need for proper education of the patient and the caregivers about the need for continued treatment.[23]

Arun R, Inbakamal S, Tharyan A, Premkumar PS (2018) accompanied a cross-sectional study to find out spousal caregiver burden and its relation with disability in schizophrenia. A total of 52 caregivers were selected as sample. It was found that there is statistically significant correlation were found between disability, duration and severity of schizophrenia, place of residence, and socioeconomic status with spousal caregiver burden. The study concluded that spouses of persons with schizophrenia experience significant caregiver burden. In addition, for reducing the spousal caregiver burden focus should be given on alleviation of disability in the management of schizophrenia. [24]

Makhal M (2018) carried out a cross-sectional study to assess influence of family burden and social support on functional disability in persons with schizophrenia at the Institute of Postgraduate Medical Education and Research (IPGMER), Kolkata, India. A total of 100 patients with a clinical diagnosis of schizophrenia and their caregivers were taken. Result shows that majority of the patients were having severe level of disability in global, interpersonal activity, communication and understanding area, whereas moderate level of disability was found in work and self-care domains. It was concluded that treatment of persons with schizophrenia should be focused on reducing family burden and enhancing social support system to improve competencies in occupation, self-care and interpersonal relationship with co-workers and significant others.[25]

Edna A, Christine A, Catherine M (2018) carried out a cross-sectional study to assess caregiver’s knowledge and attitude regarding care of schizophrenia at

Mathari teaching and referral hospital, Kenya. A total of 303 respondents participated in the study, by utilizing systemic sampling technique. The study reveals that 63% of respondents were female. Among 303 respondents 218 (72%) of the respondents did not know the name of the condition the patient was diagnosed with. Knowledge on schizophrenia significantly depended on the age of the caregiver and the length of time the caregiver was knowing the patient and taking care of the patient. Despite this, caregivers who have spent a long period with the patient are 3 times more likely to have a more positive attitude and be more knowledgeable compared to those who have spent a lesser period with schizophrenia patient. Increasing the level of knowledge regarding the condition makes the caregiver more effective in their role as the patient's support system.[26]

Srikanth D M, Popuri S, Chaukimath SP (2018) disseminated a study to find out burden in caregivers of patients with chronic schizophrenia. A total of 84 people with schizophrenia and their primary care givers were selected as sample. It was found that severity of burden increased with the severity of illness and declining in patient's level of functioning. And burden was reduced with improvement in patients by adopting treatment. Besides this, care givers who suffered from any associated medical illnesses reported significantly higher levels of burden. The study concluded that for improving the functioning level of schizophrenia patient's caregivers need support for their own physical and mental well-being. [27]

Chinwe FI, et al (2017) accompanied a study to find out Burden of care amongst caregivers who are first degree relatives of patients with schizophrenia. A total of 255 patients and caregivers were selected as sample. The study reveals, that 49% of caregivers experienced high burden of care. In addition, it was found that older caregiver's age and illness severity in the patient had weak to moderate positive correlation with burden of care. Poor functioning of the patient leads to rise in caregiver's burden. Along with this low level of education of the caregiver, psychiatric morbidity in the caregiver and poor patient functioning was the independent predictors of the burden in caregivers. The study concluded that routine screening and early psychological intervention would help to reduce negative consequences of caregiving.[28]

Bansal S, Arora R, Garg PD (2017) shows that among 34 caregivers, majority of the caregivers were parents, married and employed. 52.9% of the caregivers experienced severe burden, 26.4% caregivers had reported moderate burden and 17.6% had reported mild burden. It was found that the level of burden experienced was having statistically significant association with total PANSS score, negative and positive symptoms, general psychopathology score and duration of illness at (p=0.00). Researcher concluded for employing positive coping strategies and reducing burden there is need for psychological assistance and social support for the vulnerable caregivers. [29]

Stanley S, Balakrishnan S, Ilangovan S (2017) conducted a cross-sectional study through survey method from caregivers in a hospital setting in Thanjavur, India. It was found that majority of the caregivers were having high perceived burden and lower QOL. Perceived burden of caregivers was not influence by patient's characteristics such as age, gender, symptoms and duration of illness, while positive and negative symptoms and the duration of illness were correlated with their QOL. The study concluded there is need for intervention for family caregivers to enable them cope more effectively with the demands of caregiving. Low resource and effective outcome strategies such as psychoeducation and participation in peer support groups should be advocated for caregivers in India.[30]

Chen S, et al (2017) carried out a study on 402 caregivers through convenience sampling technique. Vignettes-based investigation were done to collect the response. It was found that among 402 respondents 28.5% caregivers using the term “schizophrenia” to describe the schizophrenia and 43.6% caregivers using the term “depression” to describe the depression. Majority of caregivers believed that “psychiatrist”, “psychologist” and “close family members” can be helpful. Caregivers considered that “becoming more physically active”, “getting out and learning more” and “receiving psychotherapy” were the helpful interventions for the patients. Beside this, 82% caregivers considered that antipsychotics were helpful for the schizophrenia and for depression 80.7% caregivers considered that antidepressants are helpful. Regarding the causes of mental illness, items related to psychosocial factors, like “daily problems’’, “work or financial problems”, and “weakness of character” were highly rated by respondents, while half of the respondents considered genetic or chemical imbalance as causes of schizophrenia. The study concluded that caregivers had adequate knowledge about treatments and interventions but there is need to improve the knowledge regarding causes of illness, speciality about the cause of schizophrenia.[31]

Raj EA, Shiri S and Jangam KV (2016) carried out a study on 32 caregivers of patients with schizophrenia by using total enumerative sampling. The study revealed that predictors of subjective burden were the variables like negative symptoms of patients, well-being, marital status, perceived severity, and relations domains of burden. No any variable was found significant for the perceived social support of caregivers. Researcher concluded that there is need for inclusive treatment services to improve the quality of life of the caregivers and to provide long-term care to patients.[32]

Koujalgi SR and Nayak RB (2016) accompanied a cross-sectional, descriptive, and correlation study to assess factors associated with family burden in schizophrenia. A total of 100 schizophrenia patients and 100 caregivers of the patients with schizophrenia were selected as sample by using stratified simple random sampling technique. Result reveals patient's advanced ages, duration of illness, poor patient income, caregivers' advanced ages, low education level, poor family income, and length of contact with patients were the factors most likely associated and also correlated positively with family care burden in schizophrenia.[33]

Hidru TH, et al (2016) disseminated a cross-sectional study on 146 caregivers of schizophrenia patients. Result revealed that, 57.5% caregivers were males and 62 were females. Greater burden was experienced by family caregivers who were single, had educational level at elementary, had low monthly income and were dissatisfied with family support. It was found that age of the caregivers, duration of providing care, family income, history of self-injury, positive scale, negative scale and general psychopathological scale were significant predictors of objective burden. Researcher concluded that there is need for social and psychological support for the caregivers to reduce their burden. [34]

Yazici E, et al (2016) carried out a study to on 88 caregivers of patients with schizophrenia. Result shows that income level and functionality of the patients were having negative correlation with burden, while age of the caregivers, daily time spent with patient and frequency of hospitalizations of patients were having positive correlation with burden. There was no significant correlation was found between the caregiver's knowledge related to schizophrenia and caregiver burden. Regarding predictor of burden, living in the same house was a positive predictor, whereas functionality and income level of the patient and education level of the caregiver were negative predictors of burden. Researcher concluded that there is need to implement rehabilitation and support programs to improve the functionality of patients. [35]

Gabrielle A, et al (2016) accompanied a cross-sectional study among 115 caregivers of the patients with schizophrenia by using consecutive sampling technique. Result shows that majority (75.7%) caregivers were predominantly females and 65.2% caregivers were males. Caregivers showed on average, mild-to-moderate burden. Higher burden was seen in caregivers who was parents and spouses of patients. In addition, higher burden of caregiving was associated with patient's inability to perform self-care, closer kinship and higher numbers of psychotic episodes in previous year. The study concluded community mental health services should include self-care interventions in rehabilitation programs for caregivers.[36]

Channaveerachari NK, et al (2015) disseminated a study to find out that Caregiver burden is associated with disability in schizophrenia. Data were collected from a community intervention program. A total of 245 schizophrenia patients were selected as sample. The study reveals that level of burden had a significant direct correlation with disability and severity of psychopathology. Beside this, it was found that duration of treatment, age of caregiver and gender of the patients were significant predictors of burden. Researcher concluded that burden of the caregiver was depends on disability experienced by patient. Therefore, measure should be taken to reduce the disability to reduce the caregiver burden. [37]

Kasturi VK, et al (2015) accompanied a cross sectional descriptive research to find out the burden among caregivers of schizophrenic clients. A total of 210 caregivers of schizophrenic clients on a psychiatric ward and outpatient department were selected by using Non-probability convenient sampling technique. Result revealed that majority (37.6%) of the caregivers had mild burden followed by 31.9% had moderate burden, and 30.5% had severe burden. There is a significant relationship between knowledge with caregivers variables like age, marital status, type of family at $p<0.05$ and occupation, residence, monthly income and relationship to patient at $p<0.01$. Researcher concluded there is an urgent need to educate clients and their caregivers regarding schizophrenia, resources in the community, stress management, rehabilitation, and follow-up.[38]

Shamsaei F, Cheraghi F, Bashirian S (2015) carried out a cross-sectional study to find out burden caregivers of schizophrenia patients. A total of 225 caregivers were selected by using convenience sampling technique. Data were collected through face-to-face interviews. Result shows that 7.6% of the caregivers experienced “no to low” burden, 23.5% “mild to moderate”, 41.8% “moderate to severe” and remaining 27.1% experienced “severe” burden. There was statistically significant association was found between level of burden and variables like age, gender, educational level, relation to care recipient, caregiving duration and duration of schizophrenia. Researcher concluded that there is need to include the caregivers in health care team and to develop supportive programs for the caregivers in context of reduce their burden.[39]

Jagannathan A, et al (2014) accompanied a study to assess predictors of family caregiver burden in schizophrenia. Data were collected from 137 caregivers of schizophrenia patients. The study reveals that total burden score had significant direct correlation with duration of illness, levels of psychopathology and disability. Whereas, perceived social support had significant inverse correlation with total burden score. There was a significant correlation between psychopathology and disability were found at ($p < 0.001$). In addition to psychopathology and disability, perceived social support were significant predictor of burden. The study concluded that focus should be given on enhancing social support for the caregivers in order to reduce burden of caregivers.[40]

Ponangi CD, et al (2014) carried out a cross-sectional study to assess caregiver burden in patients with schizophrenia. A total of 50 caregivers of persons with schizophrenia attending the psychiatry outpatient and inpatient department of a hospital were selected as sample. Caregiver burden was assessed by self-designed proforma comprising sections on socio-demographic details, Positive and Negative Syndrome Scale (PANSS) and Pai and Kapoor’s Interview Schedule. It was found that burden of care was high in both subjective and objective scales and factors like female sex, middle age and severity of illness had effect on extent of burden. The burden of care was significantly high and the severity of illness had a correlation with the burden of care on the family members. It also showed that burden of care was more in male patients and in the age group of 30 to 40 years. Researcher concluded that various risk factors for burden must be identified and measures must be taken for the caregivers who are at risk to experience more burden in terms of support to caregivers.[41]

Rajeswari MN, Sherrin S (2014) disseminated a descriptive study to find out caregiver burden in families of patients with schizophrenia at Sowmanasya hospital, Tiruchirappalli. A total of 79 family members of patients with schizophrenia were adopted to collect the data by using purposive sampling technique. Caregiver burden scale by Thara, Padmavati, Kumar & Srinivasan was used to assess the burden of caregivers. The study reveals that 74.7% of the respondents had knowledge about Mental illness and remaining (25%) had no knowledge about mental illness. Half of the respondents (51%) had high level of burden and remaining (49 %) of the respondent's burden was found to be low. Researcher concluded that family orientation interventions need to be developed to reduce burden.[42]

Adam G, et al (2014) carried out a qualitative study to explore caregiver burden in schizophrenia. A total of 19 caregivers of schizophrenia patients were selected. Data were collected by using face-to-face qualitative interview. It was found that people with schizophrenia were largely dependent upon caregivers for their care. Caregivers subsequently reported lacking time for their own work and other responsibilities. Caregiver burden frequently manifested as being fatigue, feeling sick and experiencing depression and anxiety. The study concluded caring for a person with schizophrenia has a significant impact on the lives of informal caregivers and alleviating caregiver burden is critical for managing individual and societal costs.[43]

Kate N, et al (2013) carried out a study to assess caregiving appraisal in schizophrenia. A total of 100 patients with schizophrenia and their primary caregivers were selected by using purposive random sampling. Result revealed that psychological morbidity was significantly influenced by severity of disease, time spent in giving care to patient per day (in hours) and the coping strategies used by the caregivers. There was no direct influence seen on subjective burden of total

PANSS score, but indirectly it influenced by total time spent in caregiving and coping. The present findings suggest that effective control over patients' symptoms would lead to reduced demand on caregivers which in turn, reduce subjective burden and psychological morbidity in the caregivers.[44]

Nirmala BP, et al (2011) explores a study to find out relationship between caregivers' burden and level of expressed emotions by the patients with schizophrenia. Data were collected from a total of 70 subjects including 35 schizophrenia patients and 35 caregivers of the patients attending day care center run by NIMHANS, in Bangalore, India. It was found that most of the caregivers were parents. Intervention programs must focus on impaired patient's functioning, and the families, ability to negotiate about these aspects, might be helpful in improving caregiver's burden and care. Besides this, more attention should be paid to the needs of the caregivers in order to alleviate their burden in managing mentally ill patients. [45]

Wai-Tong C, Sally W C, Morrissey J (2007) accompanied a cross-sectional descriptive study on 203 family caregivers. Result revealed that higher level of caregiver burden was seen in those families who lived in a family with poorer functioning, worse health status and less satisfaction of social support. The burden score of caregivers was positively correlated with their age. Whereas, it was negatively correlated with their monthly household income and number of family members living with patient. The social support was the best predictor of caregiver burden. Researcher concluded that helping families to maintain and enhance a supportive social network may represent a useful means to reduce family burden in schizophrenia.[46]

Parabiaghi A, et al (2007) disseminated a study on 51 caregivers of patients with schizophrenia. It was found that baseline levels of family burden were high in worrying and urging domains. 51% of caregivers experienced significant emotional distress. Severity of family burden were found to be related with higher patients' psychopathology, higher numbers of patient-rated needs, patient's lower global functioning and patients' poorer quality of life. Researcher concluded a policy addressing the caring burden of informal caregivers beyond patients' symptoms reduction should be considered.[47]

Alejandra C, et al (2006) accompanied a study to find out burden of care in families of patients with schizophrenia. A total of 41 relatives of patients with schizophrenia who were attending a public mental health outpatient service in the province of Arica, Chile, were selected as sample. It was found that all the caregivers show a very high degree of burden, especially caregivers who were mothers of the patient, older in age, with low educational level, caregivers who was unemployed and who are taking care of younger patients. Researcher concluded that close monitoring should be done for the caregiver’s mental health and the provision of family intervention and psycho-social support should be given more concern.[48]

SUMMARY:

This chapter discussed about the literature review, which is related to knowledge of caregivers regarding schizophrenia and burden of caregivers related to schizophrenia.

CHAPTER III

METHODOLOGY

CHAPTER III

METHODOLOGY

For any research work methodology of the investigation is of vital importance. According to Polit and Beck: Methodology refers to the ways of obtaining, organizing and analyzing data. A methodology decision depends on the nature of the research question. Methodology in research can be considered to be the theory of correct scientific decision.[18]

In this chapter, the researcher explained research methodology which includes research approach, research design, setting of study, sample and sampling technique, development and description of tool, content validity, reliability of tool, pilot study, data collection, plan of data analysis and plan for information booklet development.

The present study was carried out to assess the knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet.

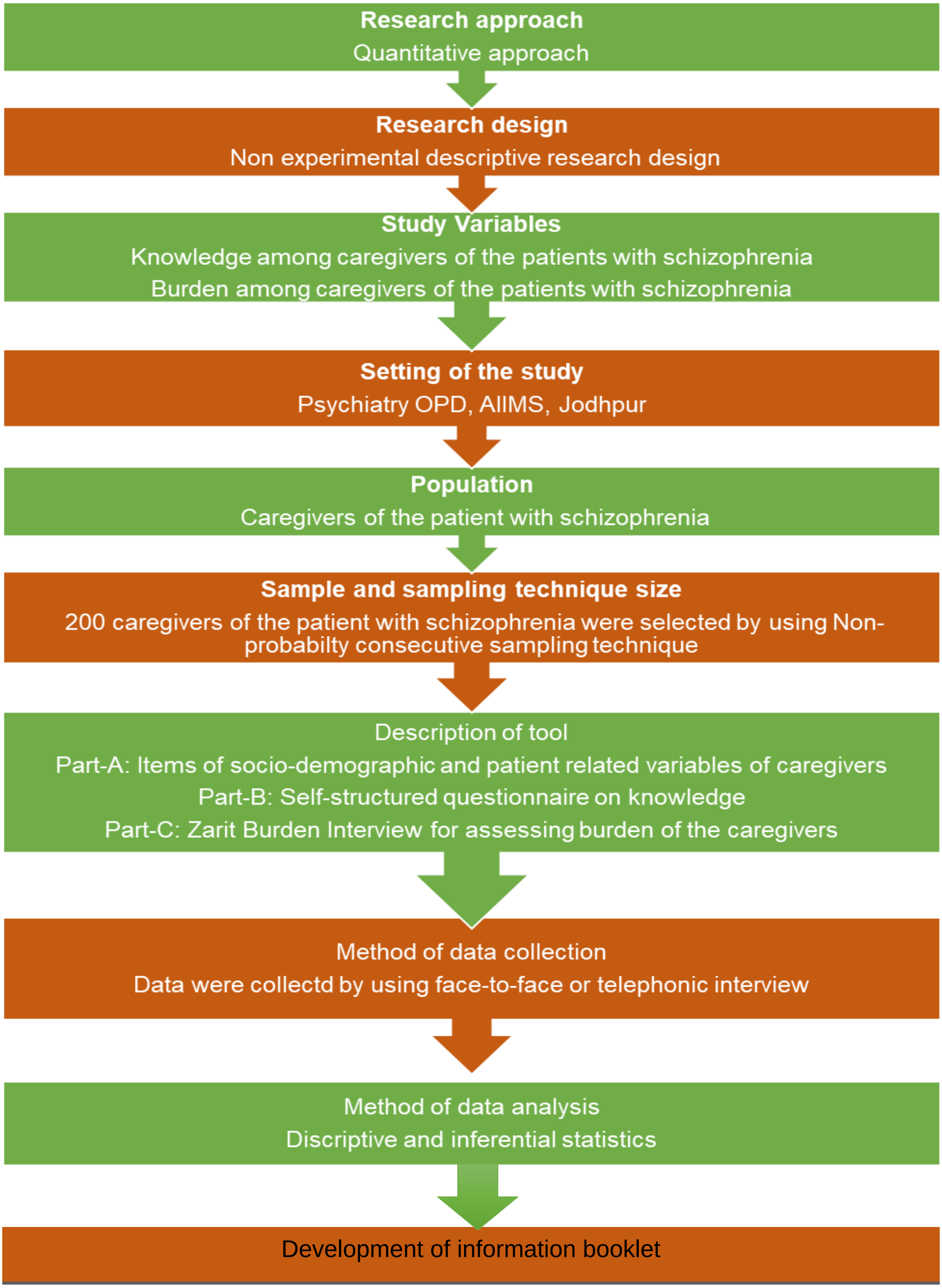


Figure IV. Schematic Presentation of Research Methodology

Research Approach:

It is an important element of the research process which governs the research designs. It involves the description of the research plan to investigate the phenomenon under study.

In present study Quantitative approach was used.

Research design:

It is a framework that is used for planning, implementation and analysis of the study. According to Polit and Beck: A research design refers to the researcher's overall plan for obtaining answer to the researcher's questions for testing the research. It incorporates some of the most important methodology decisions that the researchers make in conducting in a research study.[18]

In the present study non-experimental descriptive research design was used.

Variables:

According to Polit and Beck: A variable is, as the name implies, something that varies. A variable is any quality of an organism, group or event or environment that takes on different values.[18]

In present study variables are categorized in following categories:

- **Study variable:**
  - Knowledge among caregivers of the patients with schizophrenia
  - Burden among caregivers of the patients with schizophrenia

- **Socio-demographic variable:** These are age, gender, education, employment status, family income and marital status
- **Patient related variables of caregivers:** These are relationship of caregiver with patient, average time spent in caring per day, impact of caregiving on employment, duration of disease for your patient and duration of staying with patient after illness

Setting of the study:

According to Polit and Beck: “Setting is an environment or physical location in which data collection take place in study’’. [18]

The present study was conducted at Psychiatry OPD, AIIMS, Jodhpur

Population:

Population is the set of people or entities to which the result of a research, are to be generalized. It referred to as universe of the research study.

Target population: It consists of the total number of people or subjects which are meeting the designated set of criteria. Target population for the present study includes caregivers of the patients with schizophrenia attending psychiatric OPD, AIIMS, Jodhpur.

Accessible population: It is the aggregate of cases that confirm to designated criteria and are also accessible as subjects for a study. Accessible population for the present study, are caregivers who will be willing and available at the time of study.

Sample and sampling technique:

Sample is the subset of population selected to participate in research study.

According to Polit and Beck: A sample is a small proportion of the population selected for the observation and analysis and which is representative of entire population. Sampling is the process of selecting a representative segment of the population under study.[18]

Sampling is necessary because it is more economical and efficient to work with the small group of elements, it improves the quality of data and results in the precision and accuracy of data. It also helps in quick study results.

In the present study, Sample comprises of the caregivers of the patients with schizophrenia and Non-probability Consecutive sampling technique was used to select the sample.

Sample size:

Sample size consists number of subjects that are examined in a study.

Sample size calculation:

Sample size is calculated through Cochran formula.

The Cochran formula is:

$$n_0 = \frac{Z^2 pq}{e^2}$$

Where:

- n_0 is the sample size.

- Z is 1.96 from Z table.
- e is the desired level of precision (i.e. the margin of error) i.e. 5% (0.05)
- p is the (estimated) proportion of the population which has the attribute in question,
- q is 1 – p.

So, for the present study, p is 0.098 (here, p is disability-adjusted life-years of schizophrenia) (Schizophrenia contributed 9.8% to the total mental disorders DALYs (2017), Lancet Psychiatry)[49] and q is 0.902.

$n_0 = ((1.96)^2 (0.098) (0.902)) / (0.05)^2 = 135.76$

In this study, a sample of 200 caregivers of the patients with schizophrenia were selected at psychiatric OPD, AIIMS, Jodhpur by using non-probability consecutive sampling technique.

Sampling technique:

It is the method i.e. used to select the samples for data collection. In present study, Non-probability Consecutive Sampling was adopted.

Consecutive sampling means recruiting all people from an accessible population who meet the eligibility criteria, over a specific time interval or for a specified sample size.[18]

Criteria for sample selection:

According to Polit and Beck: These criteria specify the characteristics that people in the population must possess in order to be included in the study.[18]

It consists of two parts: -

Inclusion criteria:

Caregivers of the patients with schizophrenia who are/can:

- Staying with patient for at least one year and taking care of the patient most of the time.
- Irrespective of gender caregivers are selected as sample.
- Above 18 year of age
- Available at the time of data collection
- Understand Hindi or English

Exclusion criteria:

Caregivers of the patients with schizophrenia who are:

- Mentally ill
- Not willing to participate
- Having speech and hearing impairment

Development and Description of tools-

A research instrument is a device used to collect data. Depending on the nature of the information to be gathered different instruments are used to conduct study.

In present study self-structured tool was prepared to assess knowledge of the caregivers and standardized tool was used to assess burden of the caregivers.

Self-structured tool was prepared after doing intensive review of research, non-research literature, books, articles, journals, project reports and different online references. Formal and informal discussions were held with the guide and opinion of the experts were also taken for drafting the self-structured tool.

Tool consists of three parts:

Part A: Questionnaires to collect socio-demographic data of caregivers of the patients with schizophrenia (Age, Gender Education**,** Employment status**,** Family income and Marital status) and questionnaire to collect data of patient related variables of caregivers (Relationship of caregiver with patient, Average time spent in caring per day, Impact of caregiving on employment**,** Duration of disease for your patient and Duration of staying with patient after illness)

Part B – Self-structured questionnaire on knowledge.

Description of tool. In present study a self – structured questionnaire was prepared to assess knowledge regarding care of the patients with schizophrenia. It has 30 items questionnaire. For each correct answer 1 mark was allotted and for each incorrect answer 0 marks was given. Knowledge was interpreted as good, average and poor.

Brief review of tool:

S.N.	Domains	Item number	No. of questions	Percentage
1.	General awareness about schizophrenia	1,2,3,4,5,6,7	7	23.34%
2.	Ability to identify symptoms	8,9,10,11	4	13.34%
3.	Measures for Safety and hygiene	12,22	2	6.66%
4.	Treatment compliance	13,14,15,16,17,18,19,20,21,27	10	33.33%
5.	Management of symptoms	23, 24, 25, 26	4	13.33%
6.	Supportive intervention	28, 29, 30	3	10%
	Total no. of questions		30	100%

Interpretation of tool:

Level of knowledge	Allotted score
Good	21-30
Average	15-20
Poor	≤14

Part C – Zarit Burden Interview for assessing burden of the caregivers.

Description of tool. In the present study, for assessing burden of the caregivers, Zarit Burden Interview was used. Permission for using Zarit burden interview has been taken from tool developer through mail. It has a 22 item 5-point likert type scale which is a standardized tool. It includes 0-4 marks for each response and score ranges from 0-88 (no burden to severe burden).

Brief review of tool:

Domains	No. of items	Cluster of items	Percentage
Burden in relationship	6	1, 8, 11, 14, 18, 20	27.27%
Emotional well being	7	2, 4, 5, 9, 10, 21, 22	31.82%
Social and family life	4	3, 6, 12, 13	18.18%
Finances	1	15	4.55%
Loss of control over one's life	4	7, 16, 17, 19	18.18%
Total	22		100%

Interpretation of tool[19]:

Level of Burden	**Allotted score**
Little or no burden	0-21
Mild to moderate burden	21-40
Moderate to severe burden	41-60
Severe burden	61-88

Validity of tool:

It is concerned with scope of coverage of the content area to be measured. More often it is applied in test of a person.

Validity of self-structured questionnaire was established by opinion of panel of eight experts from the field of psychiatry and psychiatric nursing, certain modifications were done with the suggestions of experts and guide. The tool was found to be valid for the study.

Reliability of tool:

It is a degree of consistency and accuracy with which an instrument measures the attributes for which it is designed to measures.

The tool was administered to 20 caregivers of the patient with schizophrenia and the reliability was determined through Kuder-Richardson Formula 20 (KR 20).

$$r_{kr\cdot 20} = \left(\frac{k}{k-1}\right)\left(1 - \frac{\sum pq}{\sigma^2}\right)$$

k= total number of test item

∑= indicates to sum

p = the proportion of the test takers who pass an item

$q = (1-p)$

σ^2 = is the variation of the entire test

Reliability of self-structured tool was 0.829 which is within acceptable range (0.7 to 1). Thus, the tool was found to be reliable.

The Cronbach's alpha value for the ZBI item was 0.93; the intra-class correlation coefficient for the test-retest reliability of the Zarit burden score was 0.89.[50]

Ethical consideration :

The ethical consideration was obtained from Institutional Ethical Committee of AIIMS, Jodhpur (IEC certificate reference number: AIIMS/IEC/2020-21/3028 Dated-01/06/2020). Permission was obtained by competent authority and prior to administration of tool informed consent was taken from the subjects and they were assured of confidentiality and autonomy to withdraw self from study at any time of data collection. For conducting telephonic interview, permission was taken from institutional ethical committee regarding changes in data collection method and permission was given through mail. Permission for using Zarit burden interview was taken from tool developer through mail.

Pilot study:

According to Polit and Beck: "Pilot study is the small version, or trial run, done in preparation for a major study. The purpose of the pilot study is two-fold: to make improvement in the research project and detect a problem that must be eradicated before the major study is attempted."[18]

Pilot study was conducted on 10% of total sample size of the main study i.e. 20 caregivers of the patients with schizophrenia through face to face interview at Psychiatric OPD, AIIMS, Jodhpur by using non-probability consecutive sampling technique.

Pilot study was done from 21/09/2020 to 26/09/2020.

Duration of pilot study 1 week.

The aim of pilot study was to assess the knowledge and burden among the caregivers of the patients with schizophrenia. The pilot study was also designed to find out the practicability and feasibility of the study.

The purpose of the study was explained and subjects were assured about the confidentiality of their responses. Verbal or written consent was obtained from the samples and then data was collected by using telephonic or face to face interview method.

Findings of the pilot study revealed that study is feasible to conduct. The plan of the statistical analysis was also determined.

Data collection procedure:

Data were collected after obtaining ethical consideration and permission from competent authority or institutional ethical committee of AIIMS, Jodhpur. For conducting telephonic interview, permission was taken from institutional ethical committee of AIIMS, Jodhpur. Sample were selected based on inclusion and exclusion criteria. Data collection was done from 28/10/2020 to 21/11/2020 by using non-probability consecutive sampling technique. Face to face or telephonic interview method were used for collecting the data. Telephonic interview method was adopted due to the pandemic COVID-19 condition. Self-introduction was given to the subjects, nature and purpose of the study was explained to them and subjects were assured about the confidentiality of their responses. Verbal or written consent were obtained from all the samples and flexible time duration was given while collecting data.

Data analysis:

It is schematic organization and synthesis of research data and the testing of research objectives using those data. It was planned to analyze the data on the basis of objectives.

After data collection, the collected data was coded and summarized by the use of Microsoft excel sheet and all the entries were cross checked to avoid any kind of error.

Analysis was done by using SPSS version 27.

Data were analyzed by using descriptive and inferential statistics.

Descriptive statistics: Frequency, percentage, mean and standard deviation were the analytical part of the descriptive statistic, which were used to describe characteristics of demographic variables, knowledge and burden score of the respondents.

Inferential statistics: Chi-square was the analytical part of inferential statistics to seek association of knowledge and burden with selected demographic variables.

Plan for information booklet development:

The information booklet aimed to improve the knowledge and reduce the burden of caregivers regarding caring the schizophrenia patients. The title of the information booklet was **“A booklet to provide information regarding caring the patients affected with schizophrenia.”** It contains information regarding domains in which caregivers were having lack of knowledge. Following domains were basis for developing information booklet:

- General awareness about schizophrenia
- Identification of symptoms
- Treatment compliance
- Management of symptoms including social skill training
- Measures for Safety and hygiene

Summary:

The research methodology gives an overview of entire process taking a research problem in scientific and systematic manner. This chapter discussed research approach, research design, variables under study, population, setting, sample and sampling technique, development and description of tool, content validity, reliability, ethical consideration, pilot study, procedure for data collection, plan for data analysis and plan for information booklet development.

CHAPTER-IV

ANALYSIS, INTERPRETATION AND DISCUSSION

CHAPTER-IV

ANALYSIS, INTERPRETATION AND DISCUSSION

Polit and Beck defined analysis as ‘‘organization and synthesis of data to answer research questions and test hypotheses.’’ The purpose of data analysis is to organize, provide structure to, and elicit meaning from research data. [18]

Polit and Beck defined that interpretation is the process of making sense of the results of the study and examining their implications. [18]

Analysis and interpretation of the data were done using descriptive and inferential statistics on the objectives of the study.

Descriptive statistics: Frequency, percentage, mean and standard deviation were the analytical part of the descriptive statistic, which were used to describe characteristics of demographic variables, knowledge and burden score of the respondents.

Inferential statistics: Chi-square was the analytical part of inferential statistics to seek association of knowledge and burden with selected demographic variables.

Data findings have been organized and presented under the following sections:

Section I: Description of socio-demographic variables of caregivers. These were described in terms of frequencies and percentage

Section II: Description of patient related variables of caregivers. These were described in terms of frequencies and percentage

Section III: Findings related to level of knowledge among caregivers of the patients with schizophrenia

- Level of knowledge
- Frequency and percentage distribution of knowledge
- Mean and SD of knowledge

Section IV: Findings related to level of burden among caregivers of the patients with schizophrenia

- Level of burden
- Frequency and percentage distribution of burden
- Mean and SD of burden

Section V: Findings related to association between level of knowledge and selected socio-demographic variables

Section VI: Findings related to association between level of knowledge and selected patient related variables of caregivers

Section VII: Findings related to association between level of burden and selected socio-demographic variables

Section VIII: Findings related to association between level of burden and selected patient related variables of caregivers

Section IX: Findings related to domain wise Mean, Mean% and SD of knowledge questionnaire showing basis of information booklet development

ORGANIZATION AND PRESENTATION OF DATA:

For organization ad presentation of data, descriptive and inferential statistics were used the data findings have been organized and presented under following sections:

Section I: Description of socio-demographic variables of caregivers. These were described in terms of frequencies and percentage

Table 1: Frequency and percentage distribution of socio-demographic variables of caregivers of the patient with schizophrenia

N-200

S. N.	Socio-demographic variables	Frequency (f)	Percentage (%)
1	**Age (in years)**		
	19-38	89	44.5
	39-59	83	41.5
	>=60	28	14
2	**Gender**		
	Male	136	68
	Female	64	32
3	**Marital status**		
	Married	150	75
	Unmarried	50	25
4	**Education**		
	No formal education	16	8
	Up to Primary	18	9
	Up to senior secondary	75	37.5
	Graduation and above	91	45.5
5	**Employment status**		
	Unemployed	71	35.5
	Self-employed	43	21.5
	Private job	52	26
	Govt. job	34	17
6	**Family income (In Rs.)**		
	<10000	53	26.5
	10000-30000	65	32.5
	30001-50000	45	22.5
	>50000	37	18.5

Description of table 1: The above table describe frequency and percentage distribution of the socio-demographic variables of caregivers of the patients with schizophrenia. Result reveals that among 200 respondents 44.5% were between the age group of 19-38, 41.5% were between the age group of 39-59 and remaining 14% participants were in the age group of greater than and equal to 60 year. In gender distribution 68% were male and 32% were female. In marital status 75% were married and remaining 25% were unmarried. In educational group 8% were having no formal education, 9% were having formal education up to primary, 37.5% were having formal education up to senior secondary and 45.5% were having formal education up to graduation and above. In employment status 35.5% were unemployed, 21.5% were self-employed, 26% were doing private job and 17% were having government job. In monthly family income 26.5% were having income <10000, 32.5% were having income between 10000-30000, 22.5% were having income between 30001-50000 and remaining 18.5% were having family income > 50000 per month.

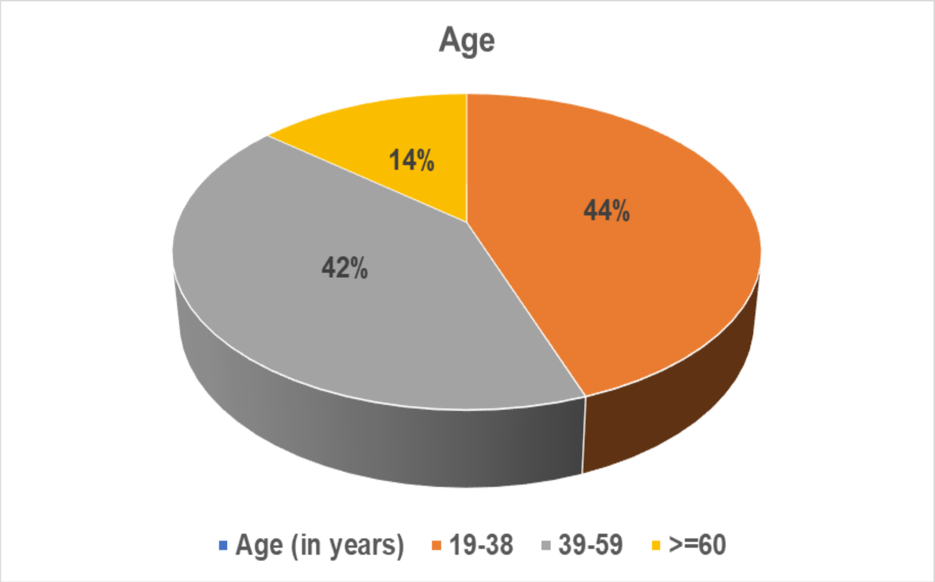


Fig. V. Pie Diagram showing percentage distribution of age of caregivers of the patients with schizophrenia

Section II: Description of patient related variables of caregivers. These were described in terms of frequencies and percentage

Table 2. Frequency and percentage distribution of patient related variables of caregivers of the patient with schizophrenia

N-200

S. N.	Patient related variables of caregivers	Frequency (f)	Percentage (%)
1	**Relationship of caregiver with patient**		
	Parents	58	29
	Spouse	51	25.5
	Children	33	16.5
	Siblings	43	21.5
	Others: Uncle, Aunt, cousins	15	7.5
2	**Average time spent in caring per day**		
	1-3 hours	92	46
	3-6 hours	45	22.5
	6-10 hours	37	18.5
	>10 hours	26	13
3	**Impact of caregiving on employment**		
	Need to take leave from work per month	36	18
	Financial condition worsened	70	35
	Become jobless	36	18
	No impact	58	29
4	**Duration of disease for your patient**		
	1-3 year	62	31
	3-6 year	41	20.5
	6-10 year	25	12.5
	>10 year	72	36
5	**Duration of staying with the patient after illness**		
	1-3 year	62	31
	3-6 year	41	20.5
	6-10 year	25	12.5
	>10 year	72	36

Description of table 2: The above table describe frequency and percentage distribution of patient related variables of caregivers of the patients with schizophrenia. Result reveals that regarding relationship of the caregivers with the patient, nearly 29% of the caregivers were parents, followed by spouses that was 25.5% of the respondents, remaining 21.5% were siblings, 16.5% were children and 7.5% were others. Regarding average time spent in caring per day 46% caregivers were spending 1-3 hours in caring for their patients per day, 22.5% were spending 3-6 hour, 18.5% were spending 6-10 hour and remaining 13% were spending >10 hours in caring per day. Regarding impact of caregiving on employment 35% of the respondents, reports worsening of financial condition, 29% reports no impact, 18% reports need to take leave from work and remaining 18% reports become jobless. Regarding duration of disease for patient 36% respondents were having patient with >10year duration of illness, 12.5% were having patients 6-10year duration of illness, 20.5% were having patients 3-6year duration of illness and remaining 31% of the caregivers were having patients with 1-3year duration of illness. Regarding duration of staying with patient after illness nearly 36% of caregivers were staying with the patient since >10year after the patient having illness followed by 1-3 year that was 31% of the respondents.

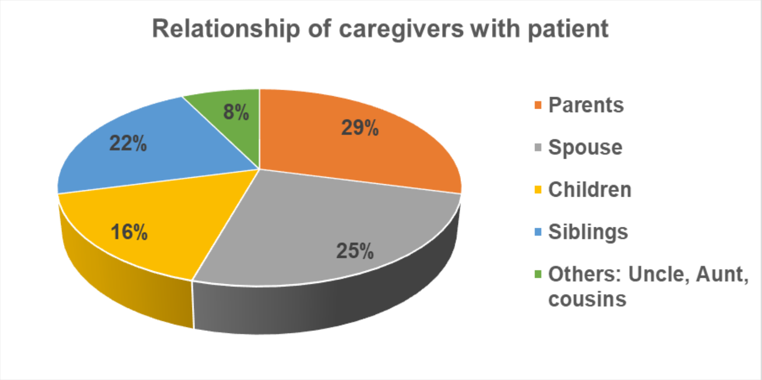


Fig. VI Pie diagram showing percentage distribution of relationship of caregivers with patients

Section III: Findings related to level of knowledge among caregivers of the patients with schizophrenia

Table 3. Level of Knowledge among caregivers of the patients with schizophrenia

N=200

S.N.	Level of knowledge	Score	Frequency (f)	Percentage (%)	Mean ± S.D.
1	**Good**	21-30	42	21	16.34 ± 4.72
2	**Average**	15-20	79	39.5	
3	**Poor**	≤14	79	39.5	

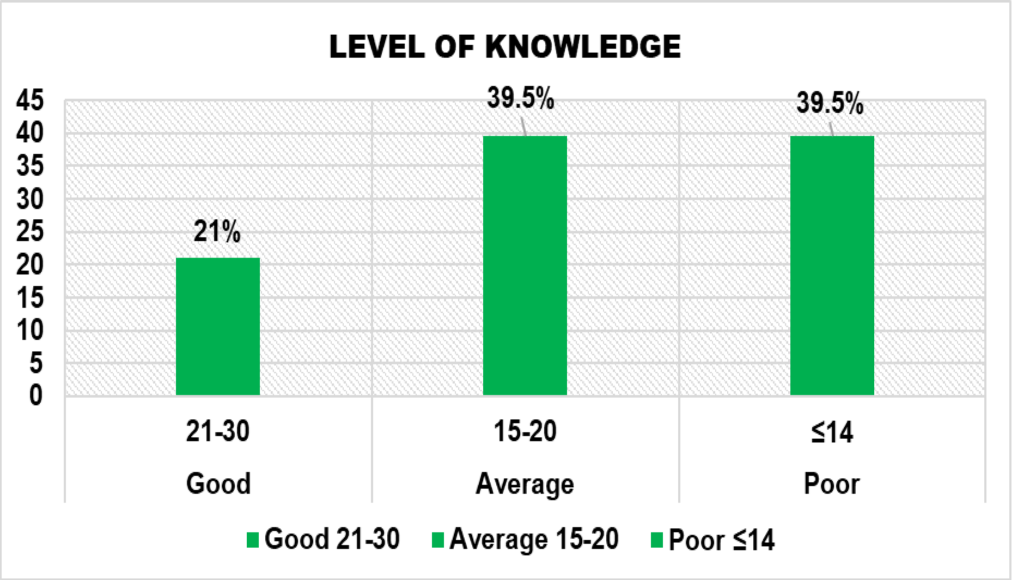


Fig. VII Bar diagram showing percentage distribution of level of knowledge among caregivers of patients with schizophrenia.

Description of Table 3 and Figure VII. Table 3 and figure VII depicts about the level of knowledge among caregivers of the patient with schizophrenia. 21% respondents were having good knowledge, 39.5% were having average knowledge and 39.5% were having poor knowledge. The mean score of the knowledge was 16.34 and standard deviation was ±4.72 which infers that overall respondents were having average level of knowledge.

Section IV: Findings related to level of burden among caregivers of the patients with schizophrenia

Table 4. Level of burden among caregivers of the patient with schizophrenia

N=200

S.N.	Level of burden	Score	Frequency (f)	Percentage (%)	Mean ± S.D.
1	**Little or no burden**	0-21	24	12	42.035 ± 15.14
2	**Mild to moderate burden**	21-40	64	32	
3	**Moderate to severe burden**	41-60	87	43.5	
4	**Severe burden**	61-88	25	12.5	

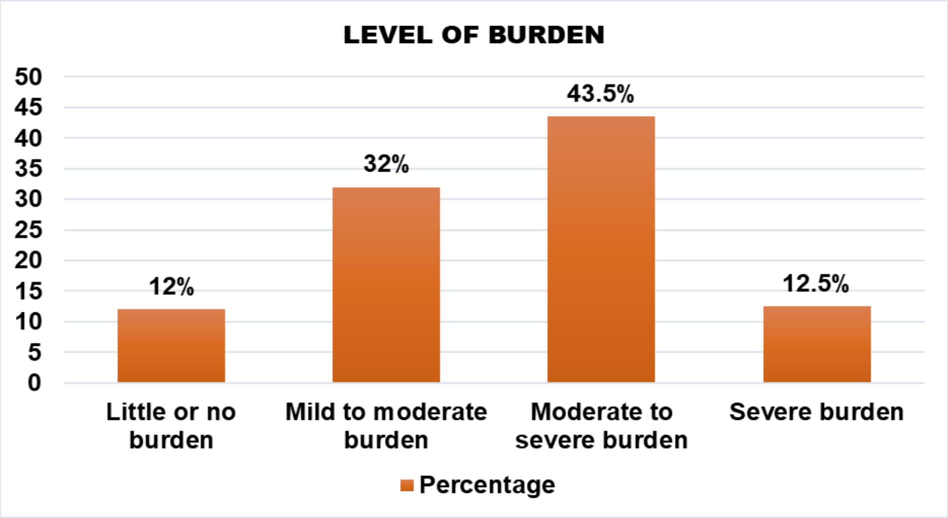


Fig. VIII Bar diagram showing percentage distribution of level of burden among caregivers of patients with schizophrenia

Description of Table 4 and Figure VIII. Table 4 and Figure VIII depicts level of burden among caregivers of the patients with schizophrenia. 12% of the respondents were having little or no burden, 32% of the respondents were having mild to moderate burden, 43.5% of the respondents were having moderate to severe burden and remaining 12.5% of the respondents were having severe burden. The mean score of the burden was 42.03 and standard deviation was ±15.14 which infers that overall, the respondents were having moderate to severe level of burden.

Section V: Findings related to association between level of knowledge and selected socio-demographic variables

Table 5. Association between level of knowledge and selected socio-demographic variables

N-200

S.N.	Socio-demographic variables	Level of knowledge			χ2 (cal)	df	p value
		Good	**Average**	**Poor**			
1	**Age (in years)**						
	19-38	23	37	29	**4.334**	**4**	**0.363**^{NS}
	39-59	15	30	38			
	>=60	4	12	12			
2	**Gender**						
	Male	31	61	44	**9.23**	**2**	**0.01***
	Female	11	18	35			
3	**Marital status**						
	Married	26	62	62	**4.862**	**2**	**0.088**^{NS}
	Unmarried	16	17	17			
4	**Education**						
	No formal education	0	1	15	**65.846**	**6**	**0***
	Up to Primary	0	6	12			
	Up to senior secondary	5	33	37			
	Graduation and above	37	39	15			
5	**Employment status**						
	Unemployed	17	17	37	**36.542**	**6**	**0***
	Self-employed	1	19	23			
	Private job	10	25	17			
	Govt. job	14	18	2			
6	**Family income (In Rs.)**						
	<10000	8	13	32	**32.579**	**6**	**0***
	10000-30000	8	26	31			
	30001-50000	11	21	13			
	>50000	15	19	3			

* - Significance ($p<0.05$), χ2 – (Chi square), NS- Not significant ($p>0.05$)

Description of Table 5. Table 5 depicts about association between level of knowledge and selected socio-demographic variables of caregivers of patients with schizophrenia. It was found that gender, education, employment status and family income were having statistically significant association with the level of knowledge at $p<0.05$, whereas, age and marital status were not found statistically significant at $p<0.05$.

Section VI: Findings related to association between level of knowledge and selected patient related variables of caregivers

Table 6. Association between level of knowledge and selected patient related variables of caregivers

N-200

S.N.	**Patient related variables of caregivers**	**Level of knowledge**			**χ2 (cal)**	**df**	**p value**
		Good	**Average**	**Poor**			
1	**Relationship of caregiver with patient**						
	Parents	11	20	27	**10.039**	**8**	**0.262^{NS}**
	Spouse	7	25	19			
	Children	9	15	9			
	Siblings	9	16	18			
	Others: Uncle, Aunt, cousins	6	3	6			
2	**Average time spent in caring per day**						
	1-3 hours	25	33	34	**8.03**	**6**	**0.236^{NS}**
	3-6 hours	9	20	16			
	6-10 hours	3	14	20			
	>10 hours	5	12	9			
3	**Impact of caregiving on employment**						
	Need to take leave from work per month	7	23	6	**20.081**	**6**	**0.003***
	Financial condition worsened	12	25	33			
	Become jobless	6	9	21			
	No impact	17	22	19			
4	**Duration of disease for your patient**						
	1-3 year	12	28	22	**4.552**	**6**	**0.602^{NS}**
	3-6 year	11	15	15			
	6-10 year	4	7	14			
	>10 year	15	29	28			
5	**Duration of staying with the patient after illness**						
	1-3 year	12	28	22	**4.552**	**6**	**0.602^{NS}**
	3-6 year	11	15	15			
	6-10 year	4	7	14			
	>10 year	15	29	28			

* - Significance ($p<0.05$), χ2 – (Chi square), NS- Not significant ($p>0.05$)

Description of Table 6. Table 6 depicts about association between level of knowledge and selected patient related variables of caregivers of patients with schizophrenia. It was found that impact of caregiving on employment were having statistically significant association with level of knowledge at $p<0.05$, whereas, relationship of caregiver with patient, average time spent in caring per day, duration of disease for your patient and duration of staying with patient after illness were not found statistically significant at $p<0.05$.

Section VII: Findings related to association between level of burden and selected socio-demographic variables

Table 7. Association between level of burden and selected socio-demographic variables

N=200

S.N.	**Socio-demographic variables**	**Level of burden**				**χ2 (cal)**	**df**	**p value**
		Little or no burden	**Mild to mod. burden**	**Mod. to severe burden**	**Severe burden**			
1	**Age (in years)**							
	19-38	13	31	39	6	**13.125**	**6**	**0.041***
	39-59	11	20	36	16			
	>=60	0	13	12	3			
2	**Gender**							
	Male	19	44	56	17	**1.919**	**3**	**0.589^{NS}**
	Female	5	20	31	8			
3	**Marital status**							
	Married	18	47	63	22	**2.647**	**3**	**0.449^{NS}**
	Unmarried	6	17	24	3			
4	**Education**							
	No formal education	2	2	6	6	**20.616**	**9**	**0.014***
	Up to Primary	2	6	8	2			
	Up to senior secondary	4	23	36	12			
	Graduation and above	16	33	37	5			
5	**Employment status**							
	Unemployed	9	25	31	6	**10.861**	**9**	**0.285^{NS}**
	Self-employed	4	9	20	10			
	Private job	5	16	25	6			
	Govt. job	6	14	11	3			
6	**Family income (In Rs.)**							
	<10000	3	22	24	4	**21.714**	**9**	**0.01***
	10000-30000	8	11	33	13			
	30001-50000	4	16	20	5			
	>50000	9	15	10	3			

* - Significance (p<0.05), χ2 – (Chi square), NS- Not significant (p>0.05)

Description of Table 7. Table 7 depicts about association between level of burden and selected socio-demographic variables. It was found that age, education and family income were statistically significant with the level of burden at p<0.05, whereas, gender, marital status and employment status were not found statistically significant at p<0.05.

Section VIII: Findings related to association between level of burden and selected patient related variables of caregivers

Table 8. Association between level of burden and selected patient related variables of caregivers

N=200

S.N.	Patient related variables of caregivers	Level of burden				χ2 (cal)	df	p value
		Little or no burden	Mild to mod. burden	Mod. to severe burden	Severe burden			
1	**Relationship of caregiver with patient**							
	Parents	3	17	31	7	**17.79**	**12**	**0.122^{NS}**
	Spouse	10	14	20	7			
	Children	2	13	17	1			
	Siblings	7	12	16	8			
	Others: Uncle, Aunt, cousins	2	8	3	2			
2	**Average time spent in caring per day**							
	1-3 hours	18	32	35	7	**14.429**	**9**	**0.108^{NS}**
	3-6 hours	1	15	21	8			
	6-10 hours	3	9	19	6			
	>10 hours	2	8	12	4			
3	**Impact of caregiving on employment**							
	Need to take leave from work per month	3	10	16	7	**25.688**	**9**	**0.002***
	Financial condition worsened	4	16	38	12			
	Become jobless	4	11	17	4			
	No impact	13	27	16	2			
4	**Duration of disease for your patient**							
	1-3 year	5	24	24	9	**12.008**	**9**	**0.213^{NS}**
	3-6 year	8	14	16	3			
	6-10 year	2	4	17	2			
	>10 year	9	22	30	11			
5	**Duration of staying with the patient after illness**							
	1-3 year	5	24	24	9	**12.008**	**9**	**0.213^{NS}**
	3-6 year	8	14	16	3			
	6-10 year	2	4	17	2			
	>10 year	9	22	30	11			

* - Significance (p<0.05), χ2 – (Chi square), NS- Not significant (p>0.05)

Description of Table 8. Table 8 depicts about association between level of burden and selected patient related variables of caregivers. It was found that impact of caregiving on employment were statistically significant with the level of burden at p<0.05, whereas, relationship of caregiver with patient, average time spent in caring per day, duration of disease for your patient and duration of staying with the patient after illness were not found statistically significant at p<0.05.

Section IX: Findings related to domain wise Mean, Mean% and SD of knowledge questionnaire showing basis of information booklet development.

Table 9. Domain wise Mean, Mean % and SD of knowledge questionnaire showing basis of information booklet development

N=200

S.N.	Domains	Item number	Mean	Mean %	SD
1	General awareness about schizophrenia	1,2,3,4,5,6,7	3.585	51.21	1.8329
2	Ability to identify symptoms	8,9,10,11	2.1	52.5	1.1253
3	Measures for Safety and hygiene	12,22	1.32	66	0.7
4	Treatment compliance	13,14,15,16,17,18,19, 20,21,27	5.43	54.3	1.8742
5	Management of symptoms	23, 24, 25, 26	1.82	45.5	1.0227
6	Supportive intervention	28, 29, 30	2.11	70.33	0.9177

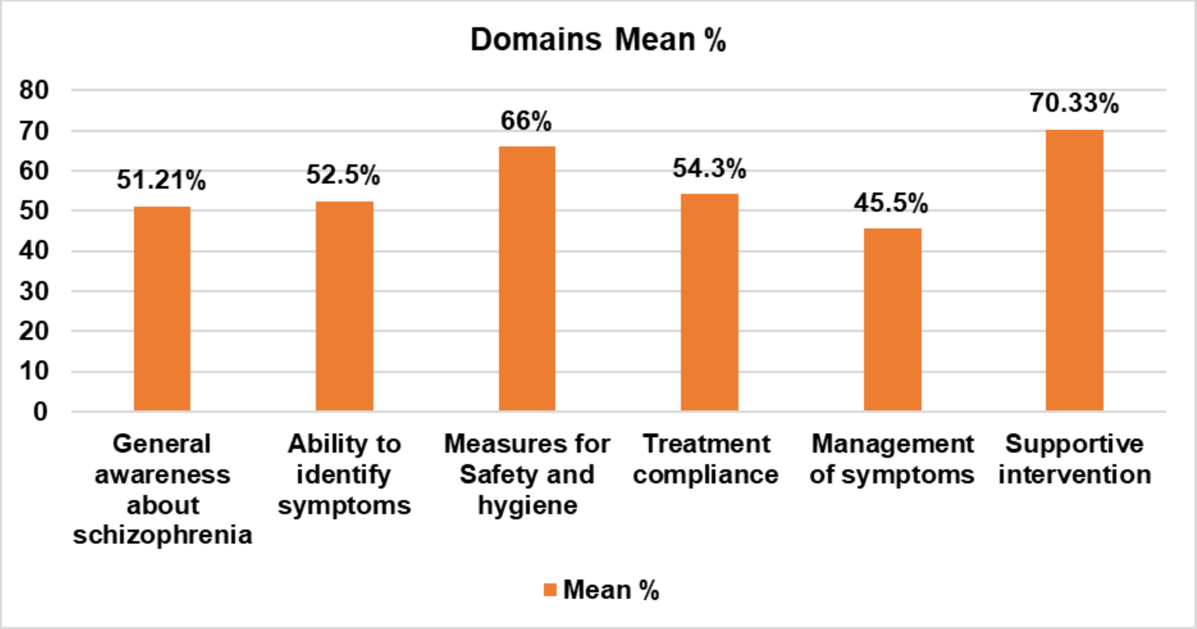


Fig. IX Mean% distribution of domains of knowledge questionnaire

Description of Table 9 and figure IX. Table 9 and figure IX shows the mean % distribution of domains of the self-structured knowledge questionnaire. It was found that respondents were having poor knowledge with 45.5 mean% related to domains like management of symptoms. Respondents were having average knowledge related to domains like general awareness about schizophrenia with 51.21 mean%, ability to identify symptoms with 52.5 mean%, treatment compliance with 54.3 mean% and measure for safety and hygiene with 66 mean%. Respondents were having good knowledge with 70.33 mean% related to domain like supportive intervention. Therefore, basis of information booklet were the domains in which caregivers had showed poor (<50 mean%) to average (between 50-70 mean%) level of knowledge.

Information booklet development:

Table-9 reveals the domains in which caregivers were having lake of knowledge, so the basis of development of information booklet were following domains:

- General awareness about schizophrenia
- Identification of symptoms
- Treatment compliance
- Management of symptoms including social skill training
- Measures for Safety and hygiene

RESULT AND DISCUSSION:

Result:

The study reveals that among 200 caregivers 21% participants were having good knowledge, 39.5% were having average knowledge and 39.5% were having poor knowledge. The mean score of the knowledge was 16.34 with the standard deviation of ±4.72. Regarding burden 12% of the caregivers were having little or no burden, 32% of the caregivers were having mild to moderate burden, 43.5% of the caregivers were having moderate to severe burden and 12.5% of the caregivers were having severe burden. The mean score of the burden was 42.03 with the standard deviation of ±15.14. Regarding knowledge gender, education, employment status, family income and impact of caregiving on employment were found statistically significant with the level of knowledge at $p<0.05$. Regarding burden age, education, family income and impact of caregiving on employment were found statistically significant with the level of burden at $p<0.05$. On the basis of mean % distribution caregivers were having lack of knowledge regarding following domains of knowledge questionnaire general awareness about schizophrenia, identification of symptoms, measures for safety and hygiene, treatment compliance and management of symptoms including social skill training. Therefore, the basis of information booklet development were these domains.

Discussion:

Current study was carried out to assess the caregiver’s knowledge and burden regarding care of the patients with schizophrenia.

Regarding the caregiver’s relationships with the patient this study found that most of the respondents were parents which is similar to the findings of Suryani S, et al (2019) who reports that Nearly two fifths of the respondents are parents. Also, in present study 25.5% were spouses and this finding is consistent with the findings of Suryani S, et al (2019) who reports that 24% of their caregivers were spouses.

Level of knowledge

In the current study emphasis is given to assess knowledge among the caregivers of the patients with schizophrenia, the findings of my study shows that 21% participants were having good knowledge, 39.5% were having average knowledge and 39.5% were having poor knowledge which is contradicting the findings of the Suryani S, et al (2019) findings which shows 31% respondents were having good knowledge, 42% were having sufficient knowledge, and 27% were having insufficient knowledge.

Level of burden:

In the current study emphasis is given to assess burden among the caregivers of the patients with schizophrenia, the findings of my study shows that 43.5% of the caregivers were having moderate to severe burden which is similar with the study of

Shamsaei F, et al (2015) which shows 41.8% caregivers experienced moderate to severe burden. Also, in current study level of burden experienced was significantly associated age and educational status, which is similar with the study of Shamsaei F, set al (2015) which shows that age and educational level were having statistically significant association with the level of burden at p<0.05.

SUMMARY:

This chapter presents analysis and interpretation of the data collected to assess the knowledge and burden among caregivers of the patients with schizophrenia. Descriptive and inferential statistics were used for analysis. Diagrammatic representation of data was done by using Pie diagram, and bar diagram. The association between level of knowledge with demographic variables and level of burden with demographic variables were determined by chi-square test.

CHAPTER-V

SUMMARY, CONCLUSION AND RECOMMENDATIONS

CHAPTER-V

SUMMARY, CONCLUSION AND RECOMMENDATIONS

Summary: The current study was conducted on caregivers of the patients with schizophrenia by using descriptive research design who are meeting the inclusion criteria. The data was collected from 200 subjects with consecutive sampling technique.

Objectives of the study:

1. To assess the level of knowledge among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur
2. To assess the level of burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur
3. To determine association between level of knowledge and selected socio-demographic and patient related variables of caregivers
4. To determine association between level of burden and selected socio-demographic and patient related variables of caregivers
5. To develop an information booklet having essential information regarding care of the patients with schizophrenia

Major findings:

- Results shows that 21% participants were having good knowledge, 39.5% were having average knowledge and 39.5% were having poor knowledge.
- Regarding burden 12% of the caregivers were having little or no burden, 32% of the caregivers were having mild to moderate burden, 43.5% of the

caregivers were having moderate to severe burden and 12.5% of the caregivers were having severe burden.

- There was a statistically significant association were found between level of knowledge and selected socio-demographic variables like gender, education, employment status, family income and with patient related variables of caregivers like impact of caregiving on employment.
- Regarding level of burden statistically significant association was seen with socio-demographic variables like age, education, family income and with patient related variables of caregivers like impact of caregiving on employment.

Limitation of study:

The study is confined to:

a) Caregivers of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur.
b) As self-structured interview schedule is used so, caregivers who are having speech and hearing problems are excluded.
c) The study is limited to the caregivers who are available at the time of the study
d) Majority of the samples were collected using telephonic interview due to pandemic COVID-19 situation.

Implication of the study:

Nursing Education

- Today nurses are no more following the traditional practices. Nurses are playing dual role now a days in hospital and education. With the help of research nurses can contribute to evidenced based care and motivate the new researchers or students for conducting such studies.

- Through continuing education and in-service education nurses can update their knowledge and practices.

Nursing Practice

- Best practice can be supported with the new and good evidences. Nurses working in clinical area may get chance to understand patient's problem in depth.
- Caregivers are most of the time neglected, current study will help the nurses to plan interventions for the caregivers thus to improve the quality of life of caregivers.
- Practice is guided by knowledge and knowledge comes with the new information, by continuously searching for evidences will definitely help to get answers for all the problems faced by nurses.

Nursing Research

- Research means re-searching for the solution or evidence to support decision making.
- Current study will help the new researcher to get an idea about such studies and planning more in-depth studies.
- This study will help the nurses to understand the problems of caregivers.

Nursing administration:

- Nursing administration should provide necessary facilities and opportunities for nursing students and staff to equip themselves with improving the knowledge of caregivers regarding schizophrenia at AIIMS, Jodhpur.

- They can identify the learning needs of caregivers of the patients with schizophrenia and plan, conduct and evaluate their teaching.

Problem faced while collecting data:

Some problems were faced during the time of data collection due to telephonic interview:

- Some respondents were not willing to share the data related to their caregiving experiences through telephonic interview because they thought it is not a reliable method to share the information
- Some respondents left the interview in between as they considered it as a lengthy process.
- Some respondents did not receive the call

Recommendation:

- Similar studies can be conducted at community level, because most of the caregivers are not reaching to the health care facility.
- Comparatives studies can be done.
- Study can be conducted on larger scale so that result can be generalized.
- Interventional studies can be conducted to improve the knowledge of the caregivers, reduce burden and to improve social support among caregivers.

Conclusion: The current study will help health care professionals to understand the impact of schizophrenia on the caregivers. Family support is an important aspect of the psychiatric treatment modality, by conducting such studies will definitely help to understand the patient and caregiver’s problems and difficulties faced during the treatment course and while providing care to the patients.

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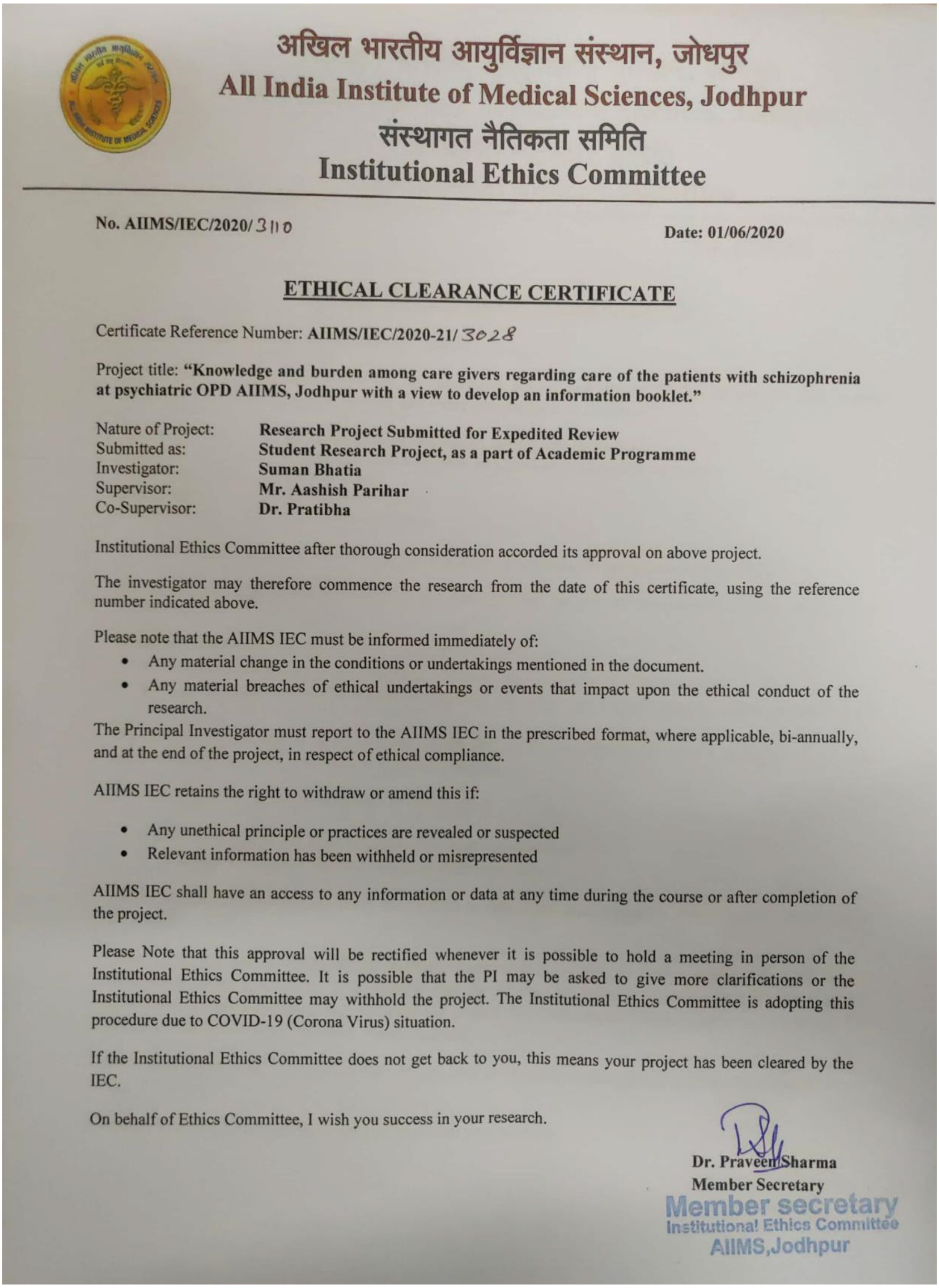
APPENDICES

APPENDIX I:

ETHICAL CLEARANCE CERTIFICATE FROM INSTITUTIONAL ETHICS COMMITTEE



अखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर
All India Institute of Medical Sciences, Jodhpur
संस्थागत नैतिकता समिति
Institutional Ethics Committee

No. AIIMS/IEC/2020/ 3110

Date: 01/06/2020

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: **AIIMS/IEC/2020-21/** 3028

Project title: **"Knowledge and burden among care givers regarding care of the patients with schizophrenia at psychiatric OPD AIIMS, Jodhpur with a view to develop an information booklet."**

Nature of Project:	**Research Project Submitted for Expedited Review**
Submitted as:	**Student Research Project, as a part of Academic Programme**
Investigator:	**Suman Bhatia**
Supervisor:	**Mr. Aashish Parihar**
Co-Supervisor:	**Dr. Pratibha**

Institutional Ethics Committee after thorough consideration accorded its approval on above project.

The investigator may therefore commence the research from the date of this certificate, using the reference number indicated above.

Please note that the AIIMS IEC must be informed immediately of:

- Any material change in the conditions or undertakings mentioned in the document.
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research.

The Principal Investigator must report to the AIIMS IEC in the prescribed format, where applicable, bi-annually, and at the end of the project, in respect of ethical compliance.

AIIMS IEC retains the right to withdraw or amend this if:

- Any unethical principle or practices are revealed or suspected
- Relevant information has been withheld or misrepresented

AIIMS IEC shall have an access to any information or data at any time during the course or after completion of the project.

Please Note that this approval will be rectified whenever it is possible to hold a meeting in person of the Institutional Ethics Committee. It is possible that the PI may be asked to give more clarifications or the Institutional Ethics Committee may withhold the project. The Institutional Ethics Committee is adopting this procedure due to COVID-19 (Corona Virus) situation.

If the Institutional Ethics Committee does not get back to you, this means your project has been cleared by the IEC.

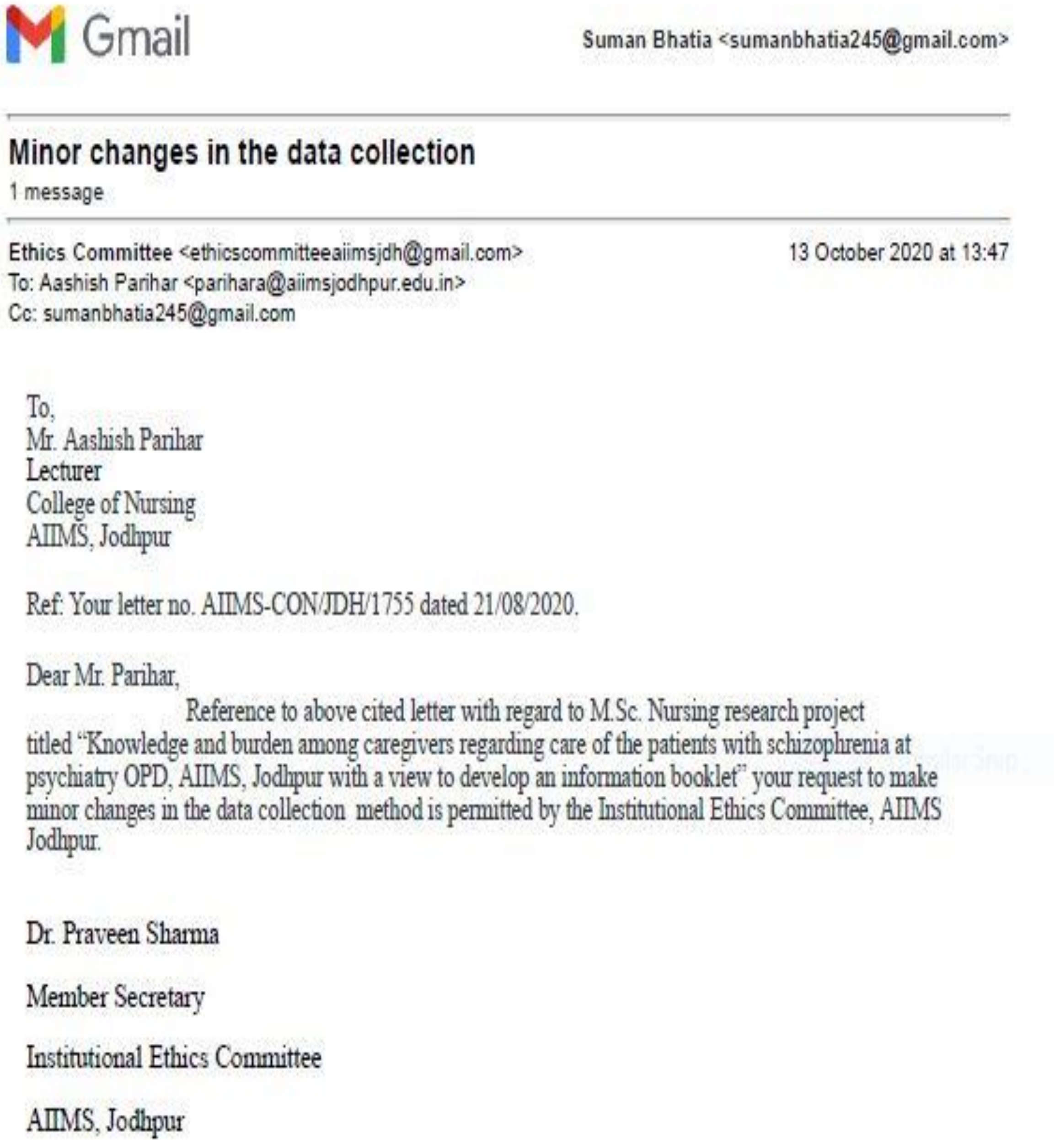
On behalf of Ethics Committee, I wish you success in your research.

Dr. Praveen Sharma
Member Secretary

Member secretary
Institutional Ethics Committee
AIIMS,Jodhpur

APPENDIX II:

PERMISSION FOR ADOPTING TELEPHONIC INTERVIEW AS A DATA COLLECTION METHOD



Suman Bhatia <sumanbhatia245@gmail.com>

Minor changes in the data collection

1 message

Ethics Committee <ethicscommitteeaiimsjdh@gmail.com> 13 October 2020 at 13:47
To: Aashish Parihar <parihara@aiimsjodhpur.edu.in>
Cc: sumanbhatia245@gmail.com

To,
Mr. Aashish Parihar
Lecturer
College of Nursing
AIIMS, Jodhpur

Ref: Your letter no. AIIMS-CON/JDH/1755 dated 21/08/2020.

Dear Mr. Parihar,

Reference to above cited letter with regard to M.Sc. Nursing research project titled "Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatry OPD, AIIMS, Jodhpur with a view to develop an information booklet" your request to make minor changes in the data collection method is permitted by the Institutional Ethics Committee, AIIMS Jodhpur.

Dr. Praveen Sharma

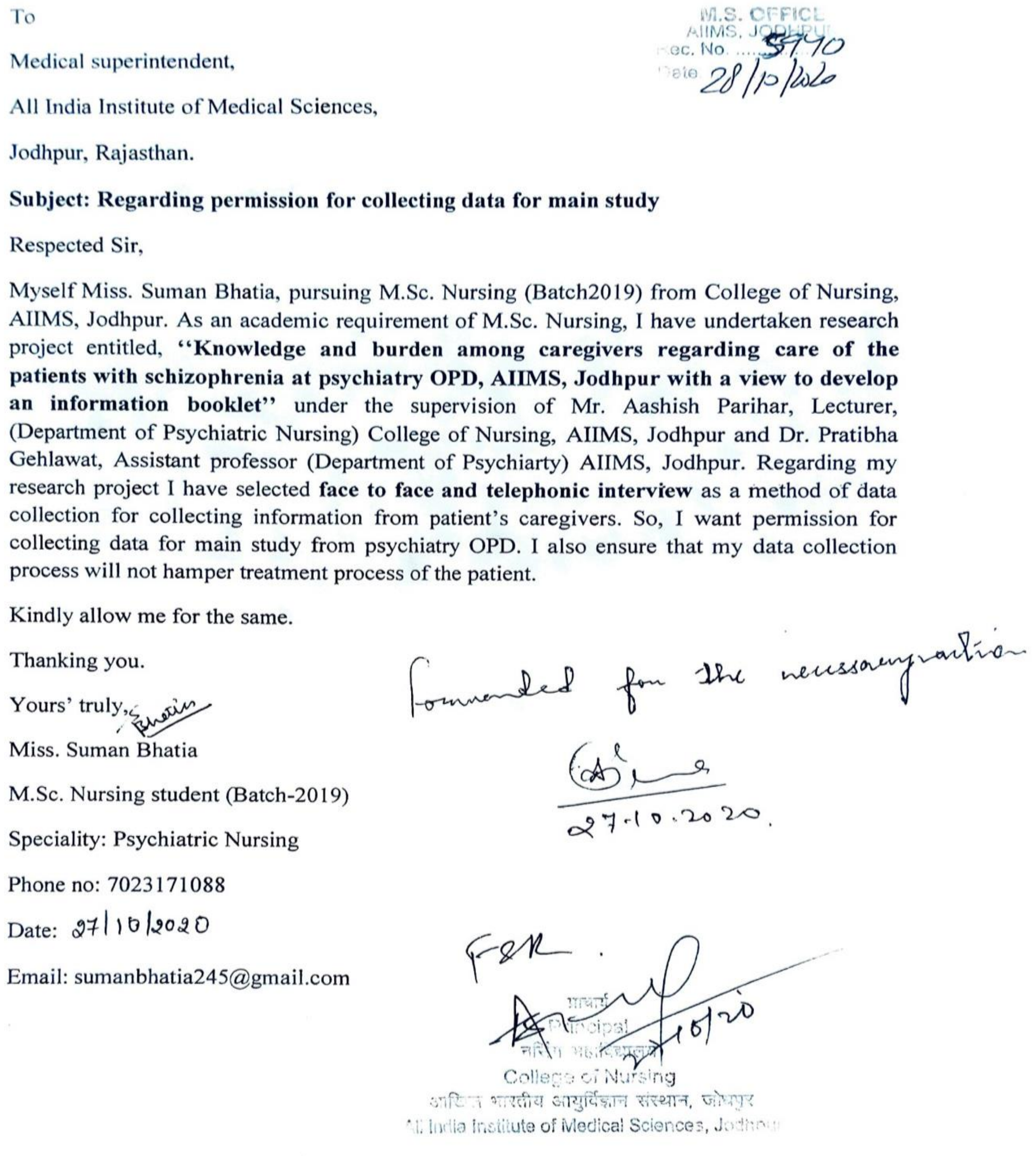
Member Secretary

Institutional Ethics Committee

AIIMS, Jodhpur

APPENDIX III:

A LETTER SEEKING PERMISSION FOR CONDUCTING MAIN STUDY



To

Medical superintendent,

All India Institute of Medical Sciences,

Jodhpur, Rajasthan.

M.S. OFFICE
AIIMS, JODHPUR
Rec. No. 5770
Date 28/10/2020

Subject: Regarding permission for collecting data for main study

Respected Sir,

Myself Miss. Suman Bhatia, pursuing M.Sc. Nursing (Batch2019) from College of Nursing, AIIMS, Jodhpur. As an academic requirement of M.Sc. Nursing, I have undertaken research project entitled, **''Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatry OPD, AIIMS, Jodhpur with a view to develop an information booklet''** under the supervision of Mr. Aashish Parihar, Lecturer, (Department of Psychiatric Nursing) College of Nursing, AIIMS, Jodhpur and Dr. Pratibha Gehlawat, Assistant professor (Department of Psychiarty) AIIMS, Jodhpur. Regarding my research project I have selected **face to face and telephonic interview** as a method of data collection for collecting information from patient's caregivers. So, I want permission for collecting data for main study from psychiatry OPD. I also ensure that my data collection process will not hamper treatment process of the patient.

Kindly allow me for the same.

Thanking you.

Yours' truly, S. Bhatia

Miss. Suman Bhatia

M.Sc. Nursing student (Batch-2019)

Speciality: Psychiatric Nursing

Phone no: 7023171088

Date: 27/10/2020

Email: sumanbhatia245@gmail.com

Forwarded for the necessary action

27.10.2020.

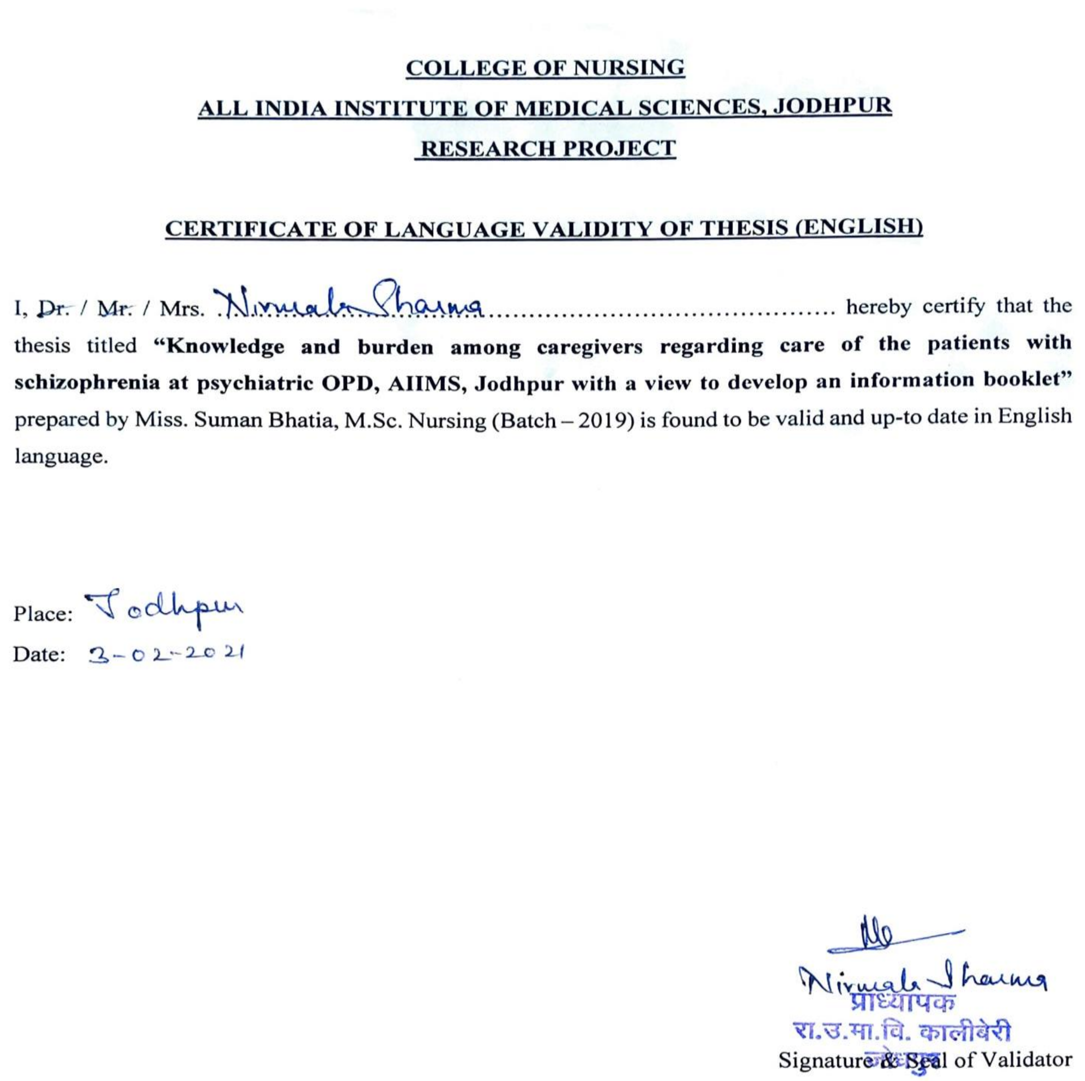
FGR.

27/10/20

प्राचार्य
Principal
नर्सिंग महाविद्यालय
College of Nursing
अखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर
All India Institute of Medical Sciences, Jodhpur

APPENDIX IV:

CERTIFICATE OF LANGUAGE VALIDITY OF THESIS (ENGLISH)



COLLEGE OF NURSING
ALL INDIA INSTITUTE OF MEDICAL SCIENCES, JODHPUR
RESEARCH PROJECT

CERTIFICATE OF LANGUAGE VALIDITY OF THESIS (ENGLISH)

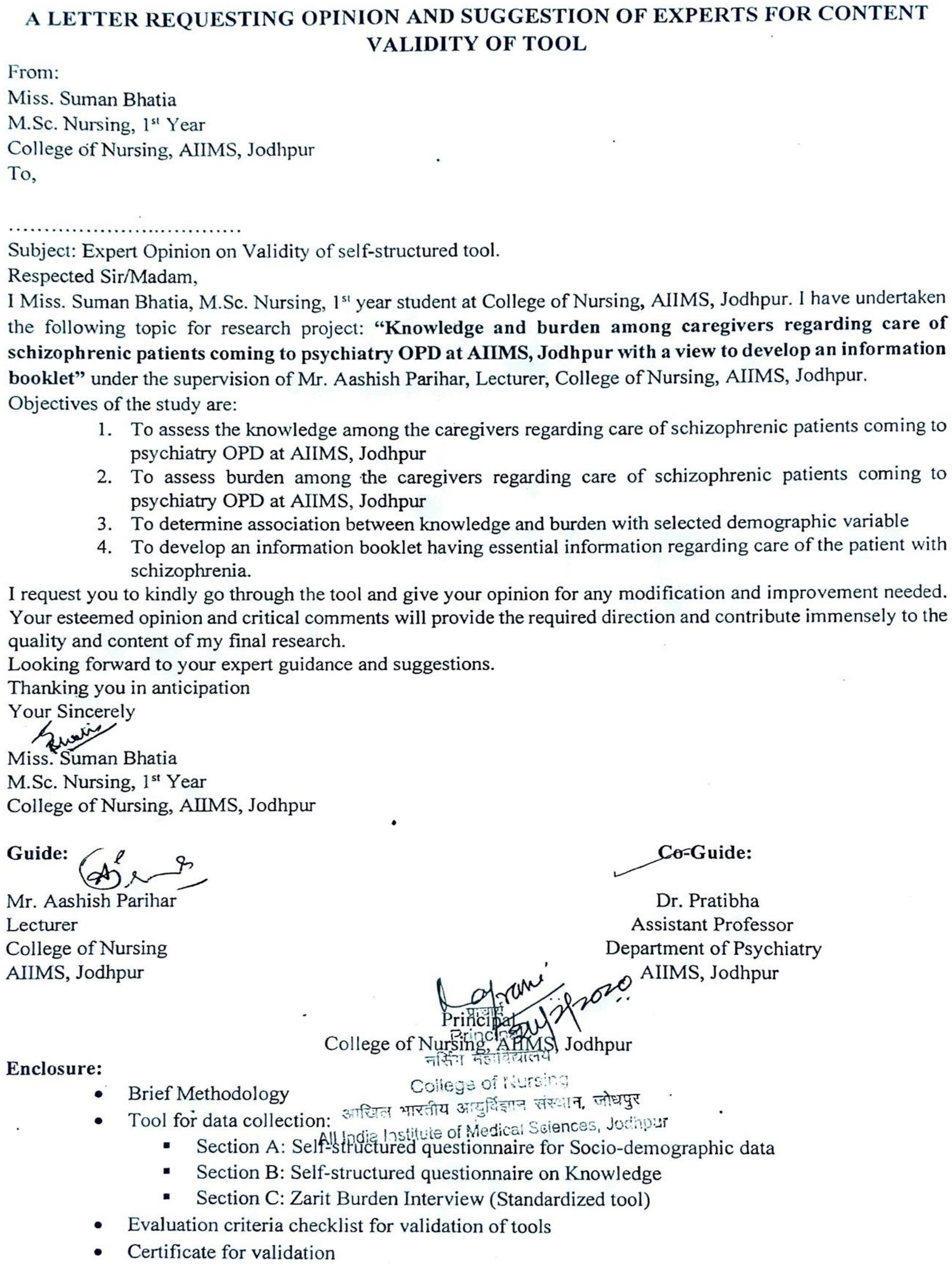
I, ~~Dr.~~ / ~~Mr.~~ / Mrs. Nirmala Sharma………………………………………… hereby certify that the thesis titled **"Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet"** prepared by Miss. Suman Bhatia, M.Sc. Nursing (Batch – 2019) is found to be valid and up-to date in English language.

Place: Jodhpur
Date: 3-02-2021

Nirmala Sharma
प्राध्यापक
रा.उ.मा.वि. कालीबेरी
जोधपुर
Signature & Seal of Validator

APPENDIX V:

LETTER REQUESTING EXPERTS FOR CONTENT VALIDITY OF TOOL



A LETTER REQUESTING OPINION AND SUGGESTION OF EXPERTS FOR CONTENT VALIDITY OF TOOL

From:
Miss. Suman Bhatia
M.Sc. Nursing, 1st Year
College of Nursing, AIIMS, Jodhpur
To,

……………………………

Subject: Expert Opinion on Validity of self-structured tool.

Respected Sir/Madam,

I Miss. Suman Bhatia, M.Sc. Nursing, 1st year student at College of Nursing, AIIMS, Jodhpur. I have undertaken the following topic for research project: **"Knowledge and burden among caregivers regarding care of schizophrenic patients coming to psychiatry OPD at AIIMS, Jodhpur with a view to develop an information booklet"** under the supervision of Mr. Aashish Parihar, Lecturer, College of Nursing, AIIMS, Jodhpur.

Objectives of the study are:

1. To assess the knowledge among the caregivers regarding care of schizophrenic patients coming to psychiatry OPD at AIIMS, Jodhpur
2. To assess burden among the caregivers regarding care of schizophrenic patients coming to psychiatry OPD at AIIMS, Jodhpur
3. To determine association between knowledge and burden with selected demographic variable
4. To develop an information booklet having essential information regarding care of the patient with schizophrenia.

I request you to kindly go through the tool and give your opinion for any modification and improvement needed. Your esteemed opinion and critical comments will provide the required direction and contribute immensely to the quality and content of my final research.

Looking forward to your expert guidance and suggestions.

Thanking you in anticipation

Your Sincerely

Miss. Suman Bhatia
M.Sc. Nursing, 1st Year
College of Nursing, AIIMS, Jodhpur

Guide:	**Co-Guide:**
Mr. Aashish Parihar	Dr. Pratibha
Lecturer	Assistant Professor
College of Nursing	Department of Psychiatry
AIIMS, Jodhpur	AIIMS, Jodhpur

31/7/2020

Principal
College of Nursing, AIIMS, Jodhpur

प्राचार्य
Principal
नर्सिंग महाविद्यालय
College of Nursing
अखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर
All India Institute of Medical Sciences, Jodhpur

Enclosure:

- Brief Methodology
- Tool for data collection:
  - Section A: Self-structured questionnaire for Socio-demographic data
  - Section B: Self-structured questionnaire on Knowledge
  - Section C: Zarit Burden Interview (Standardized tool)
- Evaluation criteria checklist for validation of tools
- Certificate for validation

APPENDIX VI:

LIST OF EXPERTS FOR TOOL VALIDATION

S.N.	NAME OF EXPERT	DESIGNATION
1.	Dr. Naresh Nebhinani	Additional professor and Head, Department of psychiatry, AIIMS, Jodhpur
2.	Dr. Mukesh Kumar Swami	Associate professor, Department of psychiatry, AIIMS, Jodhpur
3.	Dr. Navratan Suthar	Assistant professor, Department of psychiatry, AIIMS, Jodhpur
4.	Mrs. Annie Kumar	Senior faculty, LHMC, CON, New Delhi
5.	Mr. Kuldeep Patidar	Associate Professor, Geetanjali college of nursing, Udaipur
6.	Mr. Vimlesh Vyas	Associate Professor, Patidar college of nursing, Ujjain
7.	Mr. Naveen Kumar Sharma	Assistant Professor, College of nursing, AIIMS, Patna
8.	Mr. Nanda Kumar paniyadi	Assistant Professor, College of nursing, AIIMS, Bhubaneshwar

APPENDIX VII

SOCIO-DEMOGRAPHIC AND PATIENT RELATED VARIABLES AND KNOWLEDGE QUESTIONNAIRE TOOL

Part A: Socio-Demographic Variable

1. **Age (In years)**

   ……….

2. **Gender**

   ……….

3. **Marital status**

   ………

4. **Education**

   ……….

5. **Employment status:**

- Unemployed
- Self employed
- Private job
- Govt. Job

6. **Family income (in Rs.)**

- < 10000
- 10000-30000
- 30001-50000
- >50000

Patient related variables of caregivers

1. **Relationship of caregiver with patient:**

- Parents
- Spouse
- Son/Daughter
- Siblings
- Others: Uncle, Aunt, cousins

2. **Average time spent in caring per day:**

- 1-3 hours
- 3-6 hours
- 6-10 hours
- >10 hours

3. **Impact of caregiving on employment:**

- Need to take leave from work per month
- Financial condition worsened
- Become jobless
- No impact

4. **Duration of disease for your patient:**

- 1-3 year
- 3-6 year
- 6-10 year
- >10 year

5. **Duration of staying with the patient after illness:**

- 1-3 year

- 3-6 year
- 6-10 year
- >10 year

Part B: Self-Structured questionnaire on knowledge

1. **Schizophrenia is:**
   a. Cardiac disorder
   b. Mental disorder
   c. Renal disorder
   d. Liver disorder
2. **Legitimate information about schizophrenia can be obtained from:**
   a. Mental Health Professionals
   b. Newspapers
   c. Friends having relative with schizophrenia
   d. Chemists
3. **The diagnosis of Schizophrenia is usually made by:**
   a. Relative
   b. Psychiatrist
   c. Friend
   d. Neighbors
4. **How a psychiatrist made a diagnosis of schizophrenia:**
   a. CT/MRI
   b. Blood test
   c. By taking detailed history and examination of the patient
   d. By doing x-ray
5. **Specialized Mental health services are provided by:**

a. Mental Health Institutions

b. General Hospitals

c. Rehabilitation Centers

d. All of the above

6. **The onset of Schizophrenia usually occurs in the age group:**

a. >40 years

b. 26-40 years

c. 15-25 years

d. <15 years

7. **Schizophrenia is caused by:**

a. Imbalance in brain chemical

b. Trauma to brain

c. Curse of god

d. Because of evil spirit

8. **Symptoms of schizophrenia include**

a. Impaired self-care

b. Disturbed sleep

c. Unusual hearing of voices and seeing objects, abnormal behavior and suspiciousness

d. All of the above

9. **The risk of self-harm in patients with Schizophrenia is relatively higher if patient have:**

a. Decreased sleep

b. Decreased self-care

c. Lack of speech

d. Suicidal ideas, comorbid depressive symptoms and commanding hallucinations

10. Changes you may not see in the thought of the patient:

a. People are talking about him/her behind his back

b. Thoughts are under control of external power

c. People conspiring against the patient

d. Cheerful

11. Abnormal/ Disorganized behavior in Schizophrenia is characterized by which of the following:

a. Behaviour may be child-like, silly and/or inappropriate for the person's chronological age

b. Behavior may be inappropriate to the context

c. Behavior may be unpredictable or agitated

d. All of the above

12. If your patient is avoiding bath, your action be:

a. Leave the patient as he/she is

b. Encourage patient to bath and assist him/her

c. Forcefully bath the patient

d. Provide bath at alternate day

13. What treatment you will seek for will schizophrenic patient:

a. Take the patient to faith—healers

b. Do worship to god to treat the illness

c. Take the patient to psychiatrist

d. Seek help from local doctors.

14. **Treatment of choice for schizophrenia is:**
    a. Dietary modification
    b. Medication with prescription of psychiatrist
    c. Exercise
    d. Isolation
15. **How much duration of treatment necessary for the schizophrenic patients?**
    a. Days
    b. Weeks
    c. Months
    d. Years
16. **Most common side effect of antipsychotic drugs:**
    a. Rashes
    b. Ear pain
    c. Hair loss
    d. Tremors, Involuntary movement, weight gain, increase muscle tone
17. **If side effect of drugs occurs, your action will be:**
    a. Immediately report to psychiatrist to adjust the dose
    b. Wait for the self-resolving of the symptoms
    c. Stop all the drugs
    d. Take to faith healers
18. **If you see improvement in your patient your action towards treatment regimen will be:**
    a. Stop the treatment without asking to doctor
    b. Continue the treatment until the patient achieve full recovery and then stop

c. Adjust the dose by yourself

d. Note down the patient progress and follow up with the doctor and adhere with treatment till full recovery

19. After a long-term treatment what is the likely outcome we can see in patient:

a. Reduction in symptoms with chances of relapse

b. Increased sleep

c. Memory loss

d. More aggressive behavior.

20. What you will do to prevent re-occurrence of the disease in your patient:

a. Provide medication on time and frequent visit to hospital even after fade of symptoms

b. After completing treatment isolate the patient in the society

c. Wait for re-occurrence of symptoms and treat at that time

d. Leave on god

21. After achieving remission follow up for the patient is required when:

a. As per the treating psychiatrist’s advice or any warning signs of relapse occur

b. Follow up is not required

c. According to the wish of the caregiver/family member

d. Once in a year

22. If your patient develops suicidal tendency your action will be:

a. Close the patient in a room

b. Tie up the patient

c. Ignore the patient

d. Remove hazardous objects from patient’s surroundings and monitor patient’s activity and take patient to psychiatrist and follow advice.

23. How will you communicate with the patient when patient is having problem of hearing voices and suspiciousness?

a. Do not argue and communicate calmly without accepting the patients thought of hearing voices and suspiciousness

b. Threaten the patient

c. Avoid the patient

d. Accept the patients thought

24. If patient is having poor verbal communication what you will do:

a. Explain the patient cause of poor verbal communication

b. Give reward to patient whenever he/she interact voluntarily

c. Don’t talk to the patient

d. Shout on patient

25. If your patient started to remain isolated and didn’t show pleasure in activity, what you will do:

a. Allow patient to remain isolated as he/she is not creating disturbance

b. Avoid the patient

c. Try to connect with patient in trustworthy manner and motivate the patient

d. Threaten the patient

26. If your patient become suspicious towards food and says that food is poisoned, what you will do:

a. Leave the patient without having any food.

b. Make the patient to have food forcefully

c. Don’t argue and allow the patient to take packed foods, fruits etc. and further seek for specialist help.
d. Assure the patient by tasting the food.

27. Cause of frequent visits or admission in psychiatric unit of the patient is:

a. Due to non-response to medicines, relapse, severity of the illness, non-compliance etc.
b. Because psychiatric illness is always life-long
c. Due to remission
d. Due to changes in season

28. Kind of environment will be suitable for the patient at home:

a. Calm, peaceful and less hazardous environment
b. Detain the patient
c. No need to provide specific environment
d. Place the patient in separate room

29. What measures should be used by patient with schizophrenia to reduce stress:

a. Alcohol or any other substance use
b. Regular exercise, relaxation and taking support from counseling and psychotherapy
c. Should isolate themselves from society
d. Stop all the drugs

30. Patient with schizophrenia can have benefits in their illness by:

a. Putting into a hospital for many years

b. By detaining in rooms

c. Getting support from family/friends and adherence to treatment

d. By worshiping to god

ANSWER KEY:

Q.N.	ANSWER	Q.N.	ANSWER	Q.N.	ANSWER
1.	b	11.	d	21.	a
2.	a	12.	b	22.	d
3.	b	13.	c	23.	a
4.	c	14.	b	24.	b
5.	d	15.	d	25.	c
6.	c	16.	d	26.	c
7.	a	17.	a	27.	a
8.	d	18.	d	28.	a
9.	d	19.	a	29.	b
10.	d	20.	a	30.	c

HINDI TOOL:

भाग अ– सामाजिक जनसांख्यिकीय चर

1. आयु (वर्ष में)

....

2. लिंग

....

3. वैवाहिक स्तर

....

4. शिक्षा

....

5. रोजगार का स्तर –

अ. बेरोजगार
ब. स्वरोजगार
स. निजी नौकरी
द. सरकारी नौकरी

6. पारिवारिक आय–

अ. 10,000 से कम

ब. 10001 से 30,000 तक

स. 30,001 से 50,000 तक

द. 50,000 से ज्यादा

देखभाल करने वालों के मरीज संबंधी चर

1. **देखभाल करने वालों का मरीज के साथ संबंध –**

अ. माता / पिता
ब. पति / पत्नि
स. पुत्र/ पुत्री
द. भाई / बहिन
य. अन्य – चाचा / चाची, बुआ, चचेरे भाई / बहिन

2. देखभाल करने में प्रतिदिन बिताया गया औसत समय –

अ. 1–3 घण्टे
ब. 3–6 घण्टे
स. 6–10 घण्टे
द. 10 से ज्यादा घण्टे

3. देखभाल का रोजगार पर प्रभाव –

अ. हर महीने काम से अवकाश की जरूरत होती है
ब. आर्थिक स्तर खराब
स. बेरोजगारी
द. कोई प्रभाव नहीं

4. आपके मरीज की बीमारी का समयान्तराल –

अ. 1 से 3 साल

ब. 3 से 6 साल

स. 6 से 10 साल

द. 10 साल से ज्यादा

5. बीमारी के बाद मरीज के साथ रहने का समयान्तराल

अ. 1 से 3 साल

ब. 3 से 6 साल

स. 6 से 10 साल

द. 10 साल से ज्यादा

भाग– ब स्वयं रचित प्रश्नावली

1. स्किजोफ्रेनिया है–

अ दिल की बीमारी

ब मानसिक बीमारी

स किडनी की बीमारी

द लीवर की बीमारी

2. स्किजोफ्रेनिया के बारे में उचित जानकारी कहाँ से प्राप्त की जा सकती है –.

अ. मानसिक स्वास्थ्य पेशेवर से (मनोचिकित्सक से)

ब. अखबार से

स. दोस्त से जिसका स्किजोफ्रेनिया से ग्रसित रिश्तेदार है

द. रसायनज्ञ से

3. स्किजोफ्रेनिया का निदान आमतौर पर किया जाता है –

अ. रिश्तेदार द्वारा

ब. मनोचिकित्सक द्वारा

स. दोस्त द्वारा

द. राजनीतिज्ञ द्वारा

4 मनोचिकित्सक स्किजोफ्रेनिया का निदान कैसे करता है –

अ. सी. टी./एम. आर. आई. स्केन द्वारा

ब. खून जॉच द्वारा

स. रोगी के विस्तृत वृतांत/शारीरिक जॉच द्वारा

द. एक्स–रे जॉच द्वारा

5. विशेष मानसिक स्वास्थ्य सुविधाऐं प्रदान की जाती है –

अ. मानसिक स्वास्थ्य संस्थान द्वारा

ब. सामान्य अस्तपताल द्वारा

स. पुनर्वास केन्द्र द्वारा

द. उपर्युक्त सभी

6. स्किजोफ्रेनिया की शुरूआत आमतौर पर किस आयु वर्ग में होती है –

अ. 40 वर्ष से अधिक आयु वर्ग में

ब. 26 से 40 वर्ष के आयु वर्ग में

स. 15 से 25 वर्ष के आयु वर्ग में

द. 15 वर्ष से कम आयु वर्ग में

7. स्किजोफ्रेनिया का कारण है –

अ. मस्तिष्क रसायन में असंतुलन द्वारा

ब. दिमागी चोट द्वारा

स. भगवान के श्राप द्वारा

द. बुरी आत्मा के कारण”

8. स्किजोफ्रेनिया का लक्षण है –

अ. खुद की देखभाल न कर पाना

ब. नींद न आना

स. असामान्य आवाजें सुनाई देना एवं वस्तुऍ दिखाई देना, असामान्य व्यवहार और शक करना आदि‘

द. उपर्युक्त सभी

9. स्किजोफ्रेनिया वाले मरीज में खुद को हानि पहुँचाने का जोखिम वास्तविक रूप से अधिक होता है यदि मरीज में निम्न लक्षण उपस्थित हो –

अ. नींद की कमी

ब. खुद की देखभाल न कर पाना

स. कम बोलना

द. आत्मघाती विचार, अवसाद के सह–लक्षण, आदेशात्मक मतिभ्रम

10. स्किजाफ्रेनिया के मरीज के विचारों में आप कौनसा परिवर्तन नही देख सकते है–

अ. लोग उसके बारे में पीठ पीछे बातें करते है

ब. विचार बाहरी शक्ति के नियंत्रण में है

स. लोग मरीज के खिलाफ साजिश करते है

द. हंसमुख रहना

11. निम्नलिखित में से कौनसा स्किजोफ्रेनिया के मरीज का असामान्य /अव्यवस्थित व्यवहार है –

अ. व्यवहार व्यक्ति की आयु के लिए बच्चे की तरह ,मूर्खतापूर्ण और अनुचित हो सकता है

ब. व्यवहार संदर्भ के लिए अनुचित हो सकता है

स. व्यवहार अप्रत्याशित या उतेजित हो सकता है

द. उपर्युक्त सभी

प्र.12 अगर आपका मरीज स्नान नहीं कर रहा है तो आप क्या करेंगे –

अ. मरीज को उसी अवस्था में छोड़ देंगे

ब. मरीज को नहाने के लिए प्रोत्साहित करेंगे और उसका सहयोग करेंगे

स. जबरदस्ती नहला देंगे

द. हर दूसरे दिन नहला देंगे

13. स्किजोफ्रेनिया के मरीज के लिए आप क्या उपचार लेंगे –

अ. मरीज को बाबा के पास ले जायेंगे

ब. बीमार को ठीक करने के लिए भगवान से प्रार्थना करेंगे

स. मरीज को मनोचिकित्सक के पास ले जायेंगे

द. स्थानीय चिकित्सक से मदद लेंगे

14. स्किजोफ्रेनिया के लिए उतम उपचार है –

अ. खान –पान में परिवर्तन

ब. मनोचिकित्सक की सलाह से दवाईयां लेना

स. व्यायाम

द. मरीज को अलग रखना

15.स्किजोफ्रेनिया के मरीज के लिए कितने समयान्तराल का उपचार जरूरी है –

अ. दिनों का

ब. सप्ताह का

स. महीनों का

द. वर्षो का

16. एंटिसाइकोटिक दवाईयों का मुख्य दुष्प्रभाव है –

अ. शरीर पर चकते

ब. कान में दर्द

स. बालों का झड़ना

द. स्पंदन (झटके), अनेच्छिक गति, वजन का बढना, मांसपेशियों की टोन का बढना

17. अगर दवाईयों का दुष्प्रभाव होता है तो आप क्या करेंगे ।

अ. तुरंत मनोचिकित्सक के पास जाएंगे और दवाईयों की मात्रा सुनिश्चित करेंगे

ब. लक्षणों के स्वतः ठीक होने का इंतजार करेंगे

स. सभी दवाईयां बंद कर देंगे

द. मरीज को बाबा के पास ले जाएंगे

18. यदि आप अपने मरीज में सुधार देखते है तो उपचार के प्रति आपकी क्या कार्यवाही होगी

अ. चिकित्सक को बिना पूछे उपचार बंद कर देंगे

ब. जब तक मरीज पूरी तरह ठीक नहीं हो जाता उपचार जारी रखेंगे और फिर उपचार बंद कर देंगे

स. रोगी की प्रगति को नोट करेगे, चिकित्सक से निरंतर सलाह लेंगे और मरीज के पूरी तरह स्वस्थ होने तक उपचार लेंगे

द. स्वयं ही दवाई की मात्रा कम कर देंगे

19. लम्बे समय तक उपचार लेने के बाद हम मरीज में क्या संभावित परिणाम देख सकते है

अ. रोग के वापस होने की संभावना के साथ रोग के लक्षणों मे कमी

ब. नींद का बढना

स. स्मरण शक्ति में कमी

द. अधिक आक्रामक व्यवहार

20. अपने मरीज के अंदर बीमारी को वापस होने से रोकने के लिए आप क्या करेंगे –

अ. समय पर दवाईयाँ देंगे और रोग के लक्षण खत्म होने के बाद भी निरंतर अस्तपताल में दिखाएंगे

ब. उपचार पूरा होने के बाद मरीज को समाज से अलग कर देंगे

स. लक्षणों के वापस आने का इंतजार करेंगे और उस वक्त उपचार लेंगे

द. भगवान पर छोड़ देंगे

21. लक्षणों में कमी के बाद मरीज के लिए पुनः जॉच की आवश्यकता कब होगी –

अ. उपचार करने वाले मनोचिकित्सक की सलाह अथवा रोग के लक्षणों का पूर्ण रूप से वापस आने का संकेत मिलते ही

ब. पुनः जॉच की आवश्यकता नहीं है

स. परिवार के सदस्यों /देखभाल करने वालों की इच्छा के अनुसार

द. वर्ष में एक बार

22. अगर आपके मरीज में आत्महत्या की प्रवृति विकसित होती है तो आप क्या करेंगे –

अ. मरीज को कमरे में बंद कर देंगे

ब. मरीज को बांध देंगे

स. मरीज को अनदेखा कर देंगे

द. मरीज के आस–पास से खतरनाक वस्तुओं को हटा देंगे, मरीज की गतिविधियों पर नजर रखेंगे, मरीज को मनोचिकित्सक के पास ले जाएंगे और उनकी सलाह का पालन करेंगे

23. अगर आपके मरीज को आवाजें सुनाई देती है और वह शक करता हो, तो आप मरीज के साथ कैसे वार्तालाप करेंगे –

अ. मरीज के शक करने तथा आवाजें सुनाई देने के विचारों को ना मानते हुए शांतिपूर्वक तरीके से वार्तालाप करेंगे एवं बहस नहीं करेंगे

ब. मरीज को डरा देंगे

स. मरीज को अनदेखा कर देंगे

द. मरीज के विचारों को स्वीकार कर लेंगे

24. अगर आपका मरीज वार्तालाप नहीं कर रहा है तो आप क्या करेंगे

अ. मरीज को बात नहीं करने का कारण समझाएंगे

ब. जब भी मरीज अपनी इच्छा से बात करेगा उसे उपहार देंगे

स. मरीज के साथ बात नहीं करेंगे

द. मरीज पर चिल्लायेंगे

25. अगर आपका मरीज सबसे अलग रहने लगे और किसी भी काम में उत्साह न दिखाए तो आप क्या करेंगे –

अ. मरीज को अलग रहने देंगे क्योंकि वह कोई परेशानी उत्पन्न नहीं कर रहा है

ब. मरीज को अनदेखा कर देंगे

स. मरीज के साथ विश्वासपूर्वक तरीके से जुड़ने की कोशिश करेंगे एवं मरीज को उत्साहित करेंगे

द. मरीज को डराएंगे

26. अगर आपका मरीज भोजन के बारे में शंकित है और कहता है कि खाने में जहर है, तो आप क्या करेंगे –

अ. मरीज को बिना खिलाए छोड देंगे

ब. मरीज को जबरदस्ती भोजन करवाएंगे

स. मरीज के साथ बहस नहीं करेंगे, उसे डिब्बा बंद खाद्य पदार्थ व फल खाने को देंगे और विशेषज्ञ की मदद लेंगे

द. खाने को स्वयं चखकर मरीज को आश्वस्त करेंगे

27. मरीज के बार–बार मनोचिकित्सा विभाग में भर्ती होने का कारण है–

अ. दवाईयों की प्रतिक्रिया नहीं होना, लक्षणों का पूर्ण रूप से वापस आना, बीमारी की गंभीरता एवं कोई अनुपालन नहीं होने के कारण

ब. क्योकि मानसिक बीमारी जीवन भर रहती है

स. लक्षणों में कमी के साथ बीमारी का दुबारा होना

द. मौसम में परिवर्तन के कारण

28. मरीज के लिए घर पर कैसा वातावरण उपयुक्त होगा –

अ. शांतिपूर्ण एवं कम खतरनाक वातावरण

ब. मरीज को नजरबंद कर देंगे

स. विशेष वातावरण प्रदान करने की जरूरत नहीं

द. मरीज को अलग कमरे में रखना

29. तनाव कम करने के लिए स्किजोफ्रेनिया के मरीज को किन उपायों का प्रयोग करना चाहिए

अ. शराब एवं किन्हीं दूसरे मादक पदार्थो का

ब. नियमित व्यायाम, आराम, परामर्श एवं मनोचिकित्सा की सहायता लेनी चाहिए

स. खुद को समाज से अलग कर लेना चाहिए

द. सभी दवाईयॉ बंद कर देनी चाहिए

30. स्किजोफ्रेनिया के मरीज को बीमारी में कैसे लाभ मिल सकता है –

अ. कई वर्षों तक अस्पताल में रखकर

ब. कमरे में नजरबंद करके

स. परिवार एवं दोस्तों से सहारा प्राप्त करके एवं निरंतर उपचार द्वारा

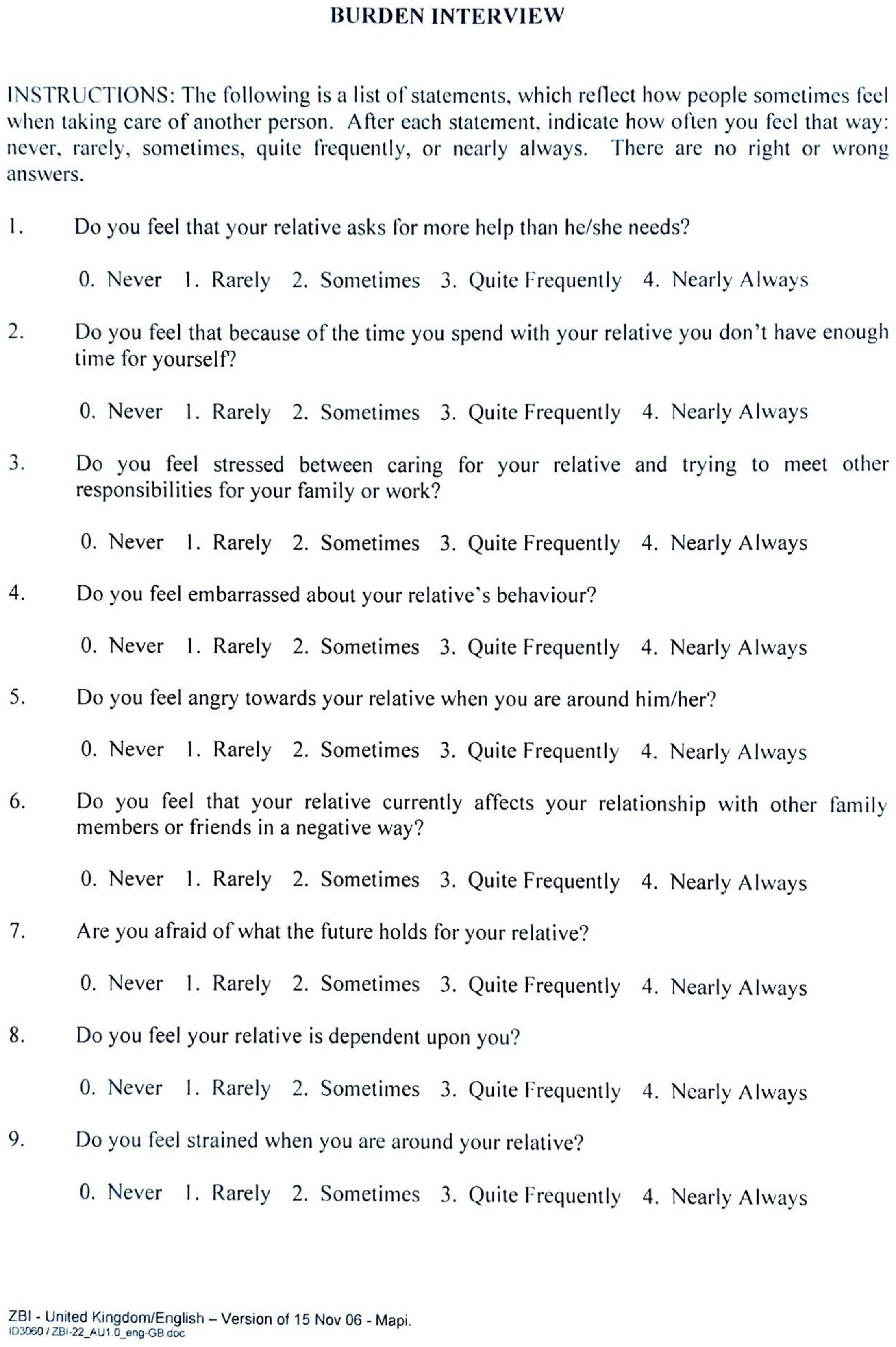
द. भगवान की पूजा करके

उत्तर कुंजी :

प्रश्न	उत्तर	प्रश्न	उत्तर	प्रश्न	उत्तर
1.	ब	11.	द	21.	अ
2.	अ	12.	ब	22.	द
3.	ब	13.	स	23.	अ
4.	स	14.	ब	24.	ब
5.	द	15.	द	25.	स
6.	स	16.	द	26.	स
7.	अ	17.	अ	27.	अ
8.	द	18.	द	28.	अ
9.	द	19.	अ	29.	ब
10.	द	20.	अ	30.	स

APPENDIX VIII:

ZARIT BURDEN INTERVIEW (ENGLISH VERSION)



BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

2. Do you feel that because of the time you spend with your relative you don't have enough time for yourself?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

4. Do you feel embarrassed about your relative's behaviour?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

5. Do you feel angry towards your relative when you are around him/her?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

7. Are you afraid of what the future holds for your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

8. Do you feel your relative is dependent upon you?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

9. Do you feel strained when you are around your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

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10. Do you feel your health has suffered because of your involvement with your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

11. Do you feel that you don't have as much privacy as you would like because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

13. Do you feel uncomfortable about having friends over because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

14. Do you feel that your relative expects you to take care of him/her, as if you were the only one he/she could depend on?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

16. Do you feel that you will be unable to take care of your relative for much longer?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

19. Do you feel uncertain about what to do about your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

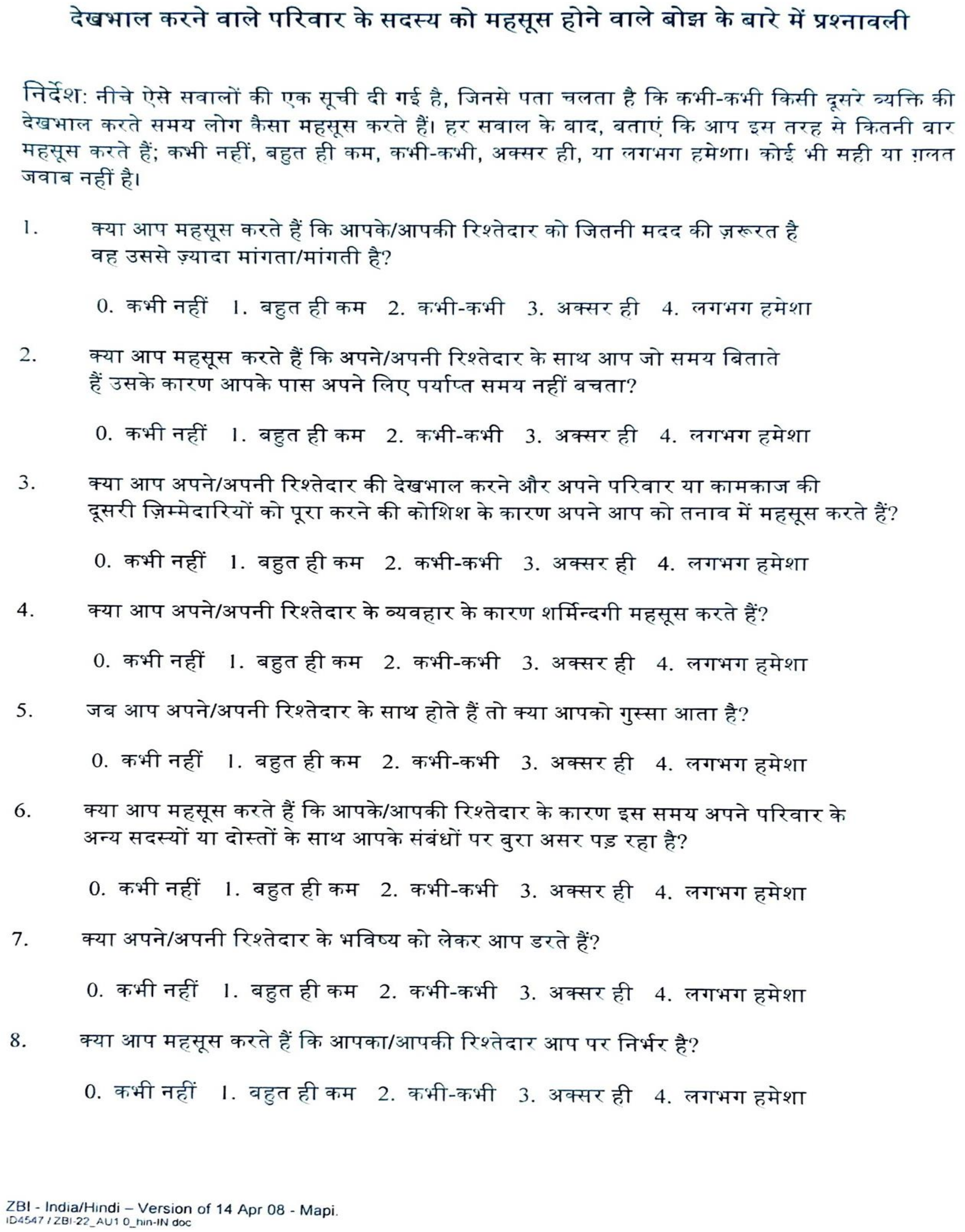
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at All 1. A Little 2. Moderately 3. Quite a Bit 4. Extremely

APPENDIX IX:

ZARIT BURDEN INTERVIEW (HINDI VERSION)



देखभाल करने वाले परिवार के सदस्य को महसूस होने वाले बोझ के बारे में प्रश्नावली

निर्देश: नीचे ऐसे सवालों की एक सूची दी गई है, जिनसे पता चलता है कि कभी-कभी किसी दूसरे व्यक्ति की देखभाल करते समय लोग कैसा महसूस करते हैं। हर सवाल के बाद, बताएं कि आप इस तरह से कितनी बार महसूस करते हैं; कभी नहीं, बहुत ही कम, कभी-कभी, अक्सर ही, या लगभग हमेशा। कोई भी सही या ग़लत जवाब नहीं है।

1. क्या आप महसूस करते हैं कि आपके/आपकी रिश्तेदार को जितनी मदद की ज़रूरत है वह उससे ज़्यादा मांगता/मांगती है?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

2. क्या आप महसूस करते हैं कि अपने/अपनी रिश्तेदार के साथ आप जो समय बिताते हैं उसके कारण आपके पास अपने लिए पर्याप्त समय नहीं बचता?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

3. क्या आप अपने/अपनी रिश्तेदार की देखभाल करने और अपने परिवार या कामकाज की दूसरी ज़िम्मेदारियों को पूरा करने की कोशिश के कारण अपने आप को तनाव में महसूस करते हैं?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

4. क्या आप अपने/अपनी रिश्तेदार के व्यवहार के कारण शर्मिन्दगी महसूस करते हैं?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

5. जब आप अपने/अपनी रिश्तेदार के साथ होते हैं तो क्या आपको गुस्सा आता है?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

6. क्या आप महसूस करते हैं कि आपके/आपकी रिश्तेदार के कारण इस समय अपने परिवार के अन्य सदस्यों या दोस्तों के साथ आपके संबंधों पर बुरा असर पड़ रहा है?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

7. क्या अपने/अपनी रिश्तेदार के भविष्य को लेकर आप डरते हैं?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

8. क्या आप महसूस करते हैं कि आपका/आपकी रिश्तेदार आप पर निर्भर है?

   0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

ZBI - India/Hindi – Version of 14 Apr 08 - Mapi.
ID4547 / ZBI-22_AU1 0_hin-IN doc

9. जब आप अपने/अपनी रिश्तेदार के साथ होते हैं तो क्या आप तनाव महसूस करते हैं?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

10. क्या आप महसूस करते हैं कि अपने/अपनी रिश्तेदार की देखभाल में लगे होने के कारण आपकी सेहत पर बुरा असर पड़ा है?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

11. क्या आप महसूस करते हैं कि अपने/अपनी रिश्तेदार के कारण आपको निजी गतिविधियों के लिए उतना समय नहीं मिल पाता है जितना आप चाहते हैं?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

12. क्या आप महसूस करते हैं कि अपने/अपनी रिश्तेदार की देखभाल के कारण आपके सामाजिक जीवन पर बुरा असर पड़ा है?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

13. क्या अपने/अपनी रिश्तेदार के कारण अपने दोस्तों को घर बुलाने में आप असुविधा महसूस करते हैं?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

14. क्या आप महसूस करते हैं कि आपका/आपकी रिश्तेदार आपसे इस तरह से देखभाल की उम्मीद करता/करती है, जैसे कि केवल आप ही हैं जिस पर वह निर्भर हो सकता/सकती है?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

15. क्या आप महसूस करते हैं कि अपने बाकी खर्चों के अलावा अपने/अपनी रिश्तेदार की देखभाल के लिए आपके पास पर्याप्त पैसे नहीं हैं?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

16. क्या आप महसूस करते हैं कि आप अब ज़्यादा दिनों तक अपने/अपनी रिश्तेदार की देखभाल नहीं कर पाएंगे?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

17. क्या आपको लगता है कि जबसे आपका/आपकी रिश्तेदार बीमार है तब से अपने जीवन पर आपका नियंत्रण नहीं रह गया है?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

18. क्या आप इच्छा करते हैं कि काश आप अपने/अपनी रिश्तेदार की देखभाल किसी और को सौंप सकते?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

19. क्या आप इस बात को लेकर अनिश्चित महसूस करते हैं कि अपने/अपनी रिश्तेदार के बारे में क्या करें?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

20. क्या आप महसूस करते हैं कि अपने/अपनी रिश्तेदार के लिए आपको और अधिक करना चाहिए?

0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

21. क्या आप महसूस करते हैं कि आप अपने/अपनी रिश्तेदार की देखभाल और बेहतर ढंग से कर सकते हैं?

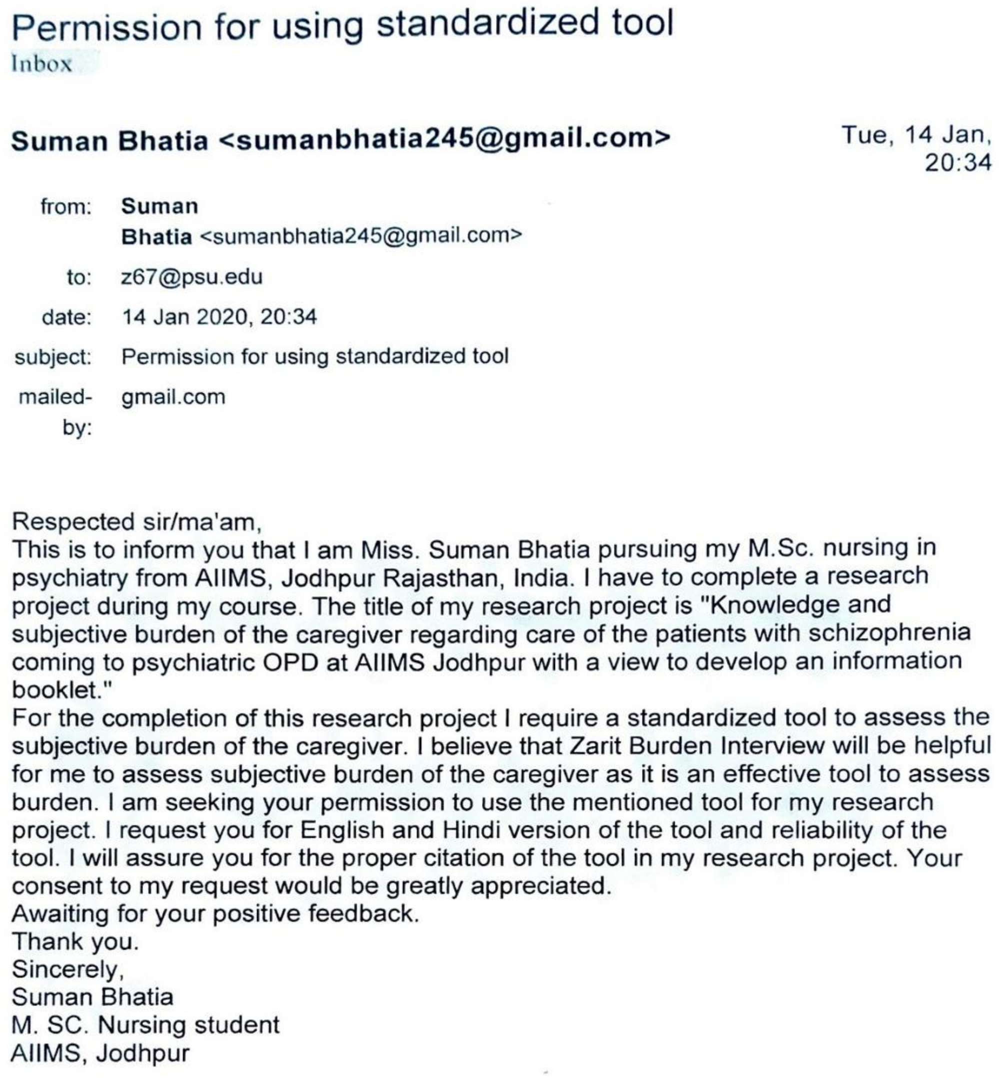
0. कभी नहीं 1. बहुत ही कम 2. कभी-कभी 3. अक्सर ही 4. लगभग हमेशा

22. कुल मिलाकर, अपने/अपनी रिश्तेदार की देखभाल करने में आप कितना बोझ महसूस करते हैं?

0. बिल्कुल नहीं 1. थोड़ा-बहुत 2. औसत 3. काफ़ी 4. बहुत अधिक

APPENDIX X:

PERMISSION TO USE ZARIT BURDEN INTERVIEW



Permission for using standardized tool

Inbox

Suman Bhatia <sumanbhatia245@gmail.com>

Tue, 14 Jan,
20:34

from: **Suman Bhatia** <sumanbhatia245@gmail.com>

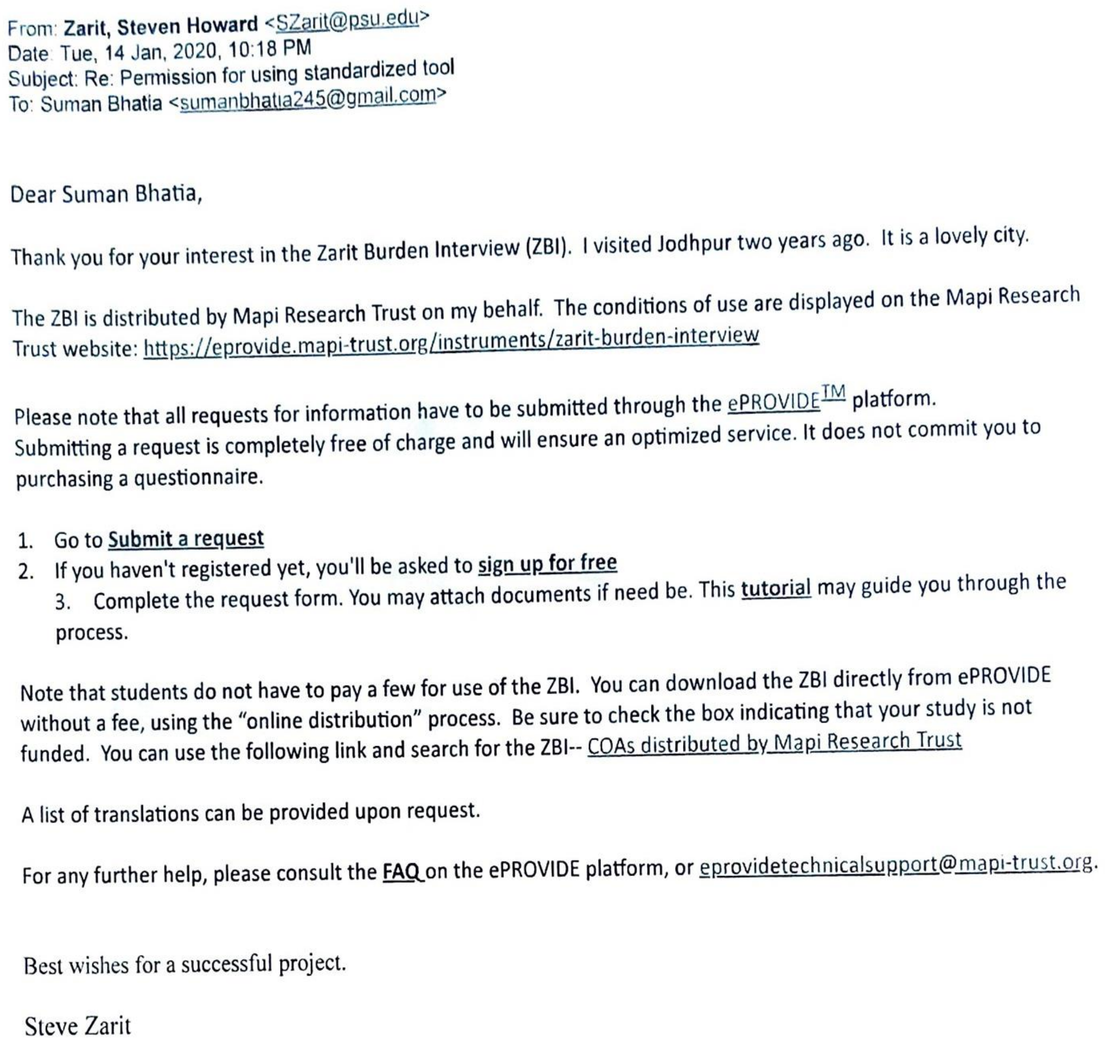
to: z67@psu.edu

date: 14 Jan 2020, 20:34

subject: Permission for using standardized tool

mailed-by: gmail.com

Respected sir/ma'am,
This is to inform you that I am Miss. Suman Bhatia pursuing my M.Sc. nursing in psychiatry from AIIMS, Jodhpur Rajasthan, India. I have to complete a research project during my course. The title of my research project is "Knowledge and subjective burden of the caregiver regarding care of the patients with schizophrenia coming to psychiatric OPD at AIIMS Jodhpur with a view to develop an information booklet."
For the completion of this research project I require a standardized tool to assess the subjective burden of the caregiver. I believe that Zarit Burden Interview will be helpful for me to assess subjective burden of the caregiver as it is an effective tool to assess burden. I am seeking your permission to use the mentioned tool for my research project. I request you for English and Hindi version of the tool and reliability of the tool. I will assure you for the proper citation of the tool in my research project. Your consent to my request would be greatly appreciated.
Awaiting for your positive feedback.
Thank you.
Sincerely,
Suman Bhatia
M. SC. Nursing student
AIIMS, Jodhpur



From: **Zarit, Steven Howard** <SZarit@psu.edu>
Date: Tue, 14 Jan, 2020, 10:18 PM
Subject: Re: Permission for using standardized tool
To: Suman Bhatia <sumanbhatia245@gmail.com>

Dear Suman Bhatia,

Thank you for your interest in the Zarit Burden Interview (ZBI). I visited Jodhpur two years ago. It is a lovely city.

The ZBI is distributed by Mapi Research Trust on my behalf. The conditions of use are displayed on the Mapi Research Trust website: https://eprovide.mapi-trust.org/instruments/zarit-burden-interview

Please note that all requests for information have to be submitted through the ePROVIDE™ platform. Submitting a request is completely free of charge and will ensure an optimized service. It does not commit you to purchasing a questionnaire.

1. Go to **Submit a request**
2. If you haven't registered yet, you'll be asked to **sign up for free**
3. Complete the request form. You may attach documents if need be. This **tutorial** may guide you through the process.

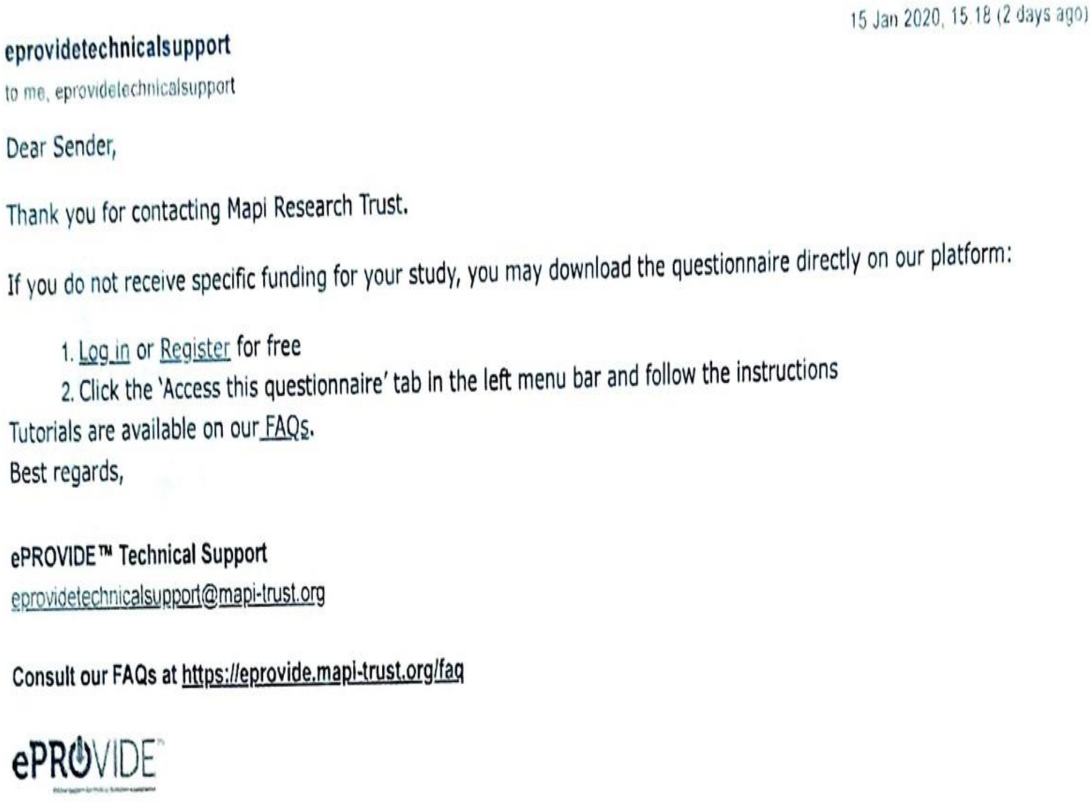
Note that students do not have to pay a few for use of the ZBI. You can download the ZBI directly from ePROVIDE without a fee, using the "online distribution" process. Be sure to check the box indicating that your study is not funded. You can use the following link and search for the ZBI-- COAs distributed by Mapi Research Trust

A list of translations can be provided upon request.

For any further help, please consult the **FAQ** on the ePROVIDE platform, or eprovidetechnicalsupport@mapi-trust.org.

Best wishes for a successful project.

Steve Zarit



eprovidetechnicalsupport

15 Jan 2020, 15.18 (2 days ago)

to me, eprovidetechnicalsupport

Dear Sender,

Thank you for contacting Mapi Research Trust.

If you do not receive specific funding for your study, you may download the questionnaire directly on our platform:

1. Log in or Register for free
2. Click the 'Access this questionnaire' tab in the left menu bar and follow the instructions

Tutorials are available on our FAQs.
Best regards,

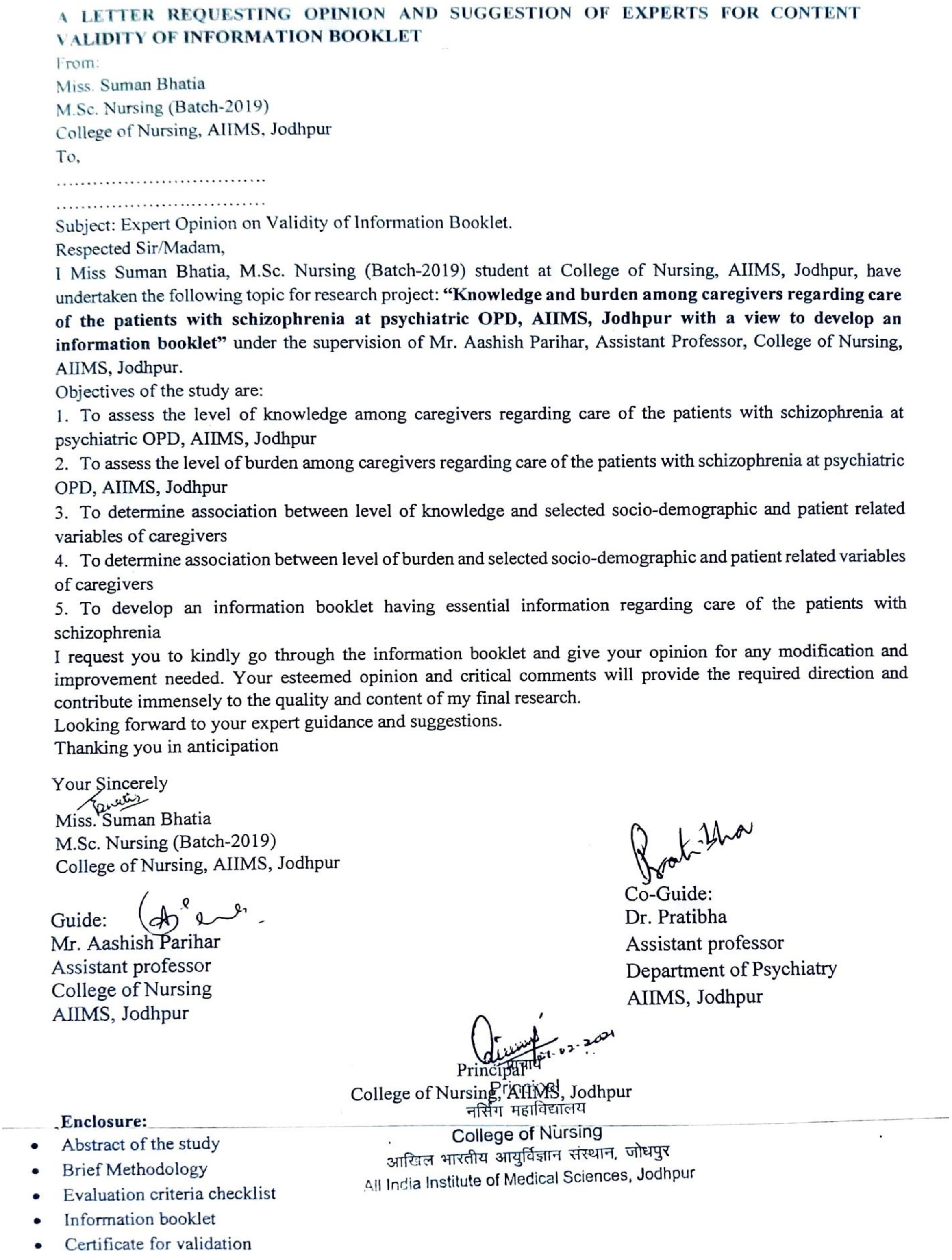
ePROVIDE™ Technical Support
eprovidetechnicalsupport@mapi-trust.org

Consult our FAQs at https://eprovide.mapi-trust.org/faq

ePROVIDE

APPENDIX XI:

A LETTER REQUESTING EXPERTS FOR CONTENT VALIDITY OF INFORMATION BOOKLET



A LETTER REQUESTING OPINION AND SUGGESTION OF EXPERTS FOR CONTENT VALIDITY OF INFORMATION BOOKLET

From:
Miss. Suman Bhatia
M.Sc. Nursing (Batch-2019)
College of Nursing, AIIMS, Jodhpur
To,
……………………………
……………………………

Subject: Expert Opinion on Validity of Information Booklet.

Respected Sir/Madam,

I Miss Suman Bhatia, M.Sc. Nursing (Batch-2019) student at College of Nursing, AIIMS, Jodhpur, have undertaken the following topic for research project: **"Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet"** under the supervision of Mr. Aashish Parihar, Assistant Professor, College of Nursing, AIIMS, Jodhpur.

Objectives of the study are:

1. To assess the level of knowledge among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur
2. To assess the level of burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur
3. To determine association between level of knowledge and selected socio-demographic and patient related variables of caregivers
4. To determine association between level of burden and selected socio-demographic and patient related variables of caregivers
5. To develop an information booklet having essential information regarding care of the patients with schizophrenia

I request you to kindly go through the information booklet and give your opinion for any modification and improvement needed. Your esteemed opinion and critical comments will provide the required direction and contribute immensely to the quality and content of my final research.

Looking forward to your expert guidance and suggestions.

Thanking you in anticipation

Your Sincerely
Miss. Suman Bhatia
M.Sc. Nursing (Batch-2019)
College of Nursing, AIIMS, Jodhpur

Co-Guide:
Dr. Pratibha
Assistant professor
Department of Psychiatry
AIIMS, Jodhpur

Guide:
Mr. Aashish Parihar
Assistant professor
College of Nursing
AIIMS, Jodhpur

21-02-2021
Principal
College of Nursing, AIIMS, Jodhpur

प्राचार्य
Principal
नर्सिंग महाविद्यालय
College of Nursing
आखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर
All India Institute of Medical Sciences, Jodhpur

Enclosure:

- Abstract of the study
- Brief Methodology
- Evaluation criteria checklist
- Information booklet
- Certificate for validation

APPENDIX XII:

LIST OF EXPERTS FOR INFORMATION BOOKLET VALIDATION

S.N.	NAME OF EXPERT	DESIGNATION
1.	Dr. Naresh Nebhinani	Additional professor and Head, Department of psychiatry, AIIMS, Jodhpur
2.	Dr. Mukesh Kumar Swami	Associate professor, Department of psychiatry, AIIMS, Jodhpur
3.	Dr. Navratan Suthar	Assistant professor, Department of psychiatry, AIIMS, Jodhpur
4.	Dr. Anish Shouan	Assistant professor, Department of psychiatry, AIIMS, Jodhpur
5.	Mr. Vimlesh Vyas	Associate Professor, Patidar college of nursing, Ujjain
6.	Mr. Naveen Kumar Sharma	Assistant Professor, College of nursing, AIIMS, Patna

APPENDIX XIII:

CONSENT FORM (ENGLISH VERSION)

Informed consent from

Title of the research study:

Name of the investigator:

Subject identification number:

I…………………………………………………………..S/o, D/o, or W/o…………………………………………………….….R/o give my full, free voluntary consent to be a part of the study "**Knowledge and burden among caregivers regarding care of the patients with schizophrenia at psychiatric OPD, AIIMS, Jodhpur with a view to develop an information booklet**". The procedure and nature of which has been explained to me in my own language to my full satisfaction. I confirm that I have had the opportunity to ask question.

I understand that my participation is voluntary and I am aware of my right to opt out of the study at any time without giving any reason.

I understand that the information collected about me and any of my medical records may be looked at by responsible individual from AIIMS, Jodhpur Rajasthan. I give permission for these individual to have access to my records.

Date …………

Place ……….

……………….

Signature / thumb impression

This to certify that the above consent has been obtained in my presence.

Date ………

Place……….

Signature of investigator…………

APPENDIX XIV:

CONSENT FORM (HINDI VERSION)

हिन्दी

<u>सहमति सूचना प्रपत्र</u>

परियोजना का शीर्षक :

अन्वेषक का नाम :

पहचान संख्या

मैं... पुत्र / पुत्री / पत्नी...निवासी, “मनोरोग ओपीडी, एम्स जोधपुर में स्किज़ोफ्रेनिया के मरीजों की देखभाल के संबंध में देखभाल करने वालों के बीच ज्ञान और बोझ का आकलन करना और एक सूचना पुस्तिका विकसित करना” नामक अध्ययन की प्रक्रिया और प्रकृति मुझे मेरी अपनी भाषा में पूर्ण संतुष्टि के साथ समझा दी गई है मैं भाग लेने के लिए अपनी पूर्ण स्वतंत्र एवं स्वेछिक सहमति देता / देती हूँ मैं पुष्टि करता / करती हूँ कि मुझे सवाल पूछने का अवसर दिया गया है मैं सहमति / सहमत हूँ कि मेरी भागीदारी स्वेछिक है और मैं अपने इस अधिकार से अवगत हूँ कि मैं किसी भी समय बिना कोई कारण दिये इस अध्ययन से अपना नाम वापस ले सकता/सकती हूँ मैं समझता / समझती हूँ कि मेरे बारे मैं एकत्र जानकारी एम्स जोधपुर के किसी भी जिम्मेदार व्यक्ति द्वारा या नियामक अधिकारियो द्वारा देखी जा सकती है मैं उपरोक्त व्यक्तियों को मेरे द्वारा दी गई जानकारी देखने की अनुमति देता / देती हूँ |

दिनांक.......... .

स्थान.............

हस्ताक्षर..........

यह प्रमाणित है कि उपरोक्त सहमति मेरी उपस्थिति में प्राप्त की गई है

दिनांक........

स्थान ....

अन्वेषक .... हस्ताक्षर

APPENDIX XV:

LIST OF FORMULAS

I. Sample size calculation formula:

Cochran formula:

$$n_0 = \frac{Z^2 pq}{e^2}$$

Where:

- n_0 is the sample size.
- Z is 1.96 from Z table.
- e is the desired level of precision (i.e. the margin of error) i.e. 5% (0.05)
- p is the (estimated) proportion of the population which has the attribute in question,
- q is 1 – p.

II. Formula for assessing reliability of self-structured tool:

Kuder-Richardson Formula 20 (KR 20):

$$r_{kr20} = \left(\frac{k}{k-1}\right)\left(1 - \frac{\sum pq}{\sigma^2}\right)$$

Where:

- k= total number of test item
- ∑= indicates to sum
- p = the proportion of the test takers who pass an item
- q = (1-p)
- σ^2 = is the variation of the entire test

APPENDIX XVI:

CODING SHEET OF SOCIO-DEMOGRAPHIC AND PATIENT RELATED VARIABLES OF CAREGIVERS

S.NO.	CONTENT	CODING
1.	**Age (in years)**	
	a) 19-38	1
	b) 39-59	2
	c) >=60	3
2.	**Gender**	
	a) Male	1
	b) Female	2
3.	**Marital status**	
	a) Married	1
	b) Unmarried	2
4.	**Education**	
	a) No formal education	1
	b) Up to Primary	2
	c) Up to senior secondary	3
	d) Graduation and above	4
5.	**Employment status:**	
	a) Unemployed	1
	b) Self employed	2
	c) Private job	3
	d) Govt. Job	4
6.	**Family income (in Rs.)**	
	a) < 10000	1
	b) 10000-30000	2
	c) 30001-50000	3
	d) >50000	4

7.	**Relationship of caregiver with patient:** a) Parents b) Spouse c) Son/Daughter d) Siblings e) Others: Uncle, Aunt, cousins	 1 2 3 4 5
8.	**Average time spent in caring per day:** a) 1-3 hours b) 3-6 hours c) 6-10 hours d) >10 hours	 1 2 3 4
9.	**Impact of caregiving on employment:** a) Need to take leave from work per month b) Financial condition worsened c) Become jobless d) No impact	 1 2 3 4
10.	**Duration of disease for your patient:** a) 1-3 year b) 3-6 year c) 6-10 year d) >10 year	 1 2 3 4
11.	**Duration of staying with the patient after illness:** a) 1-3 year b) 3-6 year c) 6-10 year d) >10 year	 1 2 3 4